Universidade de Aveiro Secção Autónoma de Ciências da Saúde
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Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus cuidadores

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Dissertação apresentada à Universidade de Aveiro para cumprimento dos requisitos necessários à obtenção do grau de Doutor em Ciências e Tecnologias da Saúde, realizada sob a orientação científica do Doutor Luís Miguel Teixeira de Jesus, Professor Coordenador na Universidade de Aveiro e co-orientação científica da Dr. Madeline Cruice, Senior Lecturer na City University London, UK.

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Dedico este estudo às pessoas com afasia, seus cuidadores e a todos os profissionais que trabalham para melhorar a qualidade de vida destas pessoas.

o júri

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Prof. Doutor Luís Miguel Teixeira de Jesus
Professor Coordenador da Universidade de Aveiro

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palavras-chave Perturbação da comunicação, afasia, cuidadores, qualidade de vida, relações sociais

resumo

A afasia é uma perturbação da comunicação adquirida, de caráter crónico, que pode alterar a vida das pessoas com afasia (PCA) e a dos seus cuidadores de forma significativa. Ambos referem frequentemente mudanças a nível social e emocional, contudo, o impacto que estas mudanças têm na qualidade de vida (QV) necessita de mais investigação.

Este estudo identifica preditores e variáveis que influenciam a QV e as relações sociais (RS) das PCA e dos seus cuidadores. É um estudo transversal descritivo, correlacional e comparativo que incluiu uma amostra de 255 indivíduos da população portuguesa em geral (43 anos de idade média e amplitude 25-84 anos; 148 mulheres e 107 homens), 25 PCA (54 anos de idade média e amplitude de 20-71 anos; 12 mulheres e 13 homens), e 25 cuidadores (idade média de 51 anos e amplitude de 26-73 anos; 17 mulheres e 8 homens). Todos os participantes responderam ao questionário World Health Organization Quality of Life Bref, ao domínio das RS do World Health Organization Quality of Life – 100 e ao Center for Epidemiologic Studies Depression Scale. Aos participantes com afasia foi ainda administrada a Bateria de Avaliação de Afasia de Lisboa, o Barthel Index, o Frenchay Activities Index, o Communication Disability Profile e o Mini-Mental State Modificado que avaliaram a linguagem, o coeficiente de afasia, as atividades, a participação e a cognição. Adicionalmente, os cuidadores completaram o Carers' Assessment of Managing Index que avalia as estratégias de *coping* utilizadas. As PCA e os seus cuidadores estão menos satisfeitos com a sua QV e RS que as pessoas da população em geral, sendo que as PCA são as que apresentam pior QV e RS. A afasia parece, portanto, ter um impacto negativo na QV e nas RS das PCA. O estado emocional é muito importante para a QV e para as RS dos três grupos. As atividades e participação das PCA têm grande influência na QV e nas RS das PCA e dos cuidadores. Adicionalmente, o estado emocional e a participação são os melhores preditores da QV das PCA e a participação o melhor preditor das RS. O estado emocional, participação e atividades da PCA são os melhores preditores da QV dos cuidadores; o estado emocional e o número de coabitantes os melhores preditores das RS dos cuidadores. A avaliação e intervenção com PCA deve contemplar todos os aspectos que influenciam a QV e RS das PCA e dos seus cuidadores para que o objectivo de melhorar a sua QV e RS seja atingido. Estes resultados são importantes para identificar e planear o apoio necessário, são úteis na orientação dos serviços prestados pelas instituições e permitem o ajuste dos programas e políticas de saúde às reais necessidades destas pessoas.

keywords Communication disability, aphasia, caregivers, quality of life, social relationships

abstract

Aphasia is a chronic acquired communication disorder that may change people with aphasia (PWA) and their caregivers' lives for ever. Social and emotional changes are frequently reported by both, although the impact of these changes in quality of life (QOL) needs further research.

This study identifies predictors and variables that influence PWA's and their caregivers' QOL and social relationships (SR). A cross-sectional descriptive, correlational and comparative study was undertaken with 255 individuals from Portuguese general population (mean age 43 years, range 25-84 years; 148 females, 107 males), 25 PWA (mean age 54 years, range 20-71; 12 females and 13 males), and 25 caregivers (mean age 51 years, range 26-73; 17 females and 8 males). All the participants completed the World Health Quality of Life Bref instrument, the SR domain of the World Health Organization Quality of Life – 100 scale, and the Center for Epidemiologic Studies Depression Scale. Participants with aphasia completed the Lisbon Aphasia Assessment Battery, Barthel Index, Frenchay Activities Index, Communication Disability Profile and the Modified Mini-Mental State which evaluated language disability, aphasia coefficient, activities, participation and cognition. In addition, caregivers completed the Carers' Assessment of Managing Index to assess coping strategies. PWA and their caregivers are less satisfied with their QOL and SR than Portuguese general population; whereas PWA have the worse QOL and SR. Thus, aphasia seems to impact negatively in their QOL and SR. Emotional status has great importance for QOL and SR among the three groups. PWA's activities and participation have great impact in both PWA's and caregivers' QOL and SR. Additionally, emotional status and participation are the best predictors of PWA's QOL. Along with these two variables, activities of the PWA are the best predictors of caregivers' QOL. Participation is the best predictor of PWA's SR; emotional status and number of cohabitants are best predictors for caregivers' SR. Aphasia assessment and intervention should take into account all the factors that influence PWA's and caregivers' QOL and SR so the central goal of enhancing it can be achieved. These results are important for identifying and planning support needs and are useful in the orientation of the activities carried out by the service providers allowing the adjustment of health programs and policies based on people's real life needs.

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List of abbreviations

ADL – Activities of daily living
BI – Barthel Index
CAMI – Carer's Assessment of Managing Index
CDP – Communication Disability Profile
CES-D – Center for Epidemiologic Studies Depression Scale
EQ-5D – EuroQol
ESOMAR - European Society for Social, Opinion and Market Research
FAI – Frenchay Activities Index
HRQOL – Health Related Quality of Life
LAAB – Lisbon Aphasia Assessment Battery
LMMS – Language Modified Mini-Mental State
MMSE – Mini Mental State Examination
MMSM – Mini-Mental State Modificado
NHP – Nottingham Health Profile
PCA – Pessoa(s) com afasia
PWA – People/person with aphasia
PWI – Psychosocial Well-Being Index
QCL – Quality of Communication Life Scale
QLI – Quality of Life Index
QOL – Quality of life
QV – Qualidade de vida
RS – Relações sociais
SAQOL – Stroke Aphasic Quality of Life Scale
SA-SIP-30 - Stroke Adapted 30-Item Version of the Sickness Impact Profile
SF-20 – Medical Outcome Study Short-Form General Health Survey
SF-36 – Short-Form General Health Survey-36
SLT – Speech and language therapy
SR – Social relationships
SS-QOL – Stroke Specific Quality of Life Scale
SWB – Subjective Well-Being
WHO – World Health Organization
WHOQOL – World Health Organization Quality of Life
WHOQOL-100 – World health Organization Quality of Life Scale - 100
WHOQOL-Bref – World health Organization Quality of Life Scale – Bref

CHAPTER 1: Introduction

Aphasia is an acquired language disability caused by brain damage, usually stroke, that affects the person's ability to communicate with others since it may compromise speaking, understanding, reading, and writing (Goodglass, 1993; Hallowell & Chapey, 2008). Aphasia affects the biopsychosocial integrity of the individuals compromising their social relationships (SR), their participation in activities, their emotional status and their QOL. These changes are unexpected and also have impact on the family and other social partners. Usually families report social and emotional changes and various difficulties communicating with the people with aphasia (PWA) (K. Brown, Worrall, Davidson, & Howe, 2011; Grawburg, Howe, Worrall, & Scarinci, 2013a, 2013b; Kitzmuller, Asplund, & Haggstrom, 2012). The extent of the impact of aphasia may be different across people, although it usually impacts in life domains and affects people's QOL. Adjustment is needed from PWA, their families, caregivers, and surrounding community.

Comprehensive aphasia treatment should include aims embracing PWA and their families learning about and adjusting to aphasia. Communication skills training, activities and life participation oriented interventions, counselling and support should be included in those treatments. Therefore, their needs and rehabilitation goals need to be identified, and gathering more data about the impact of this pathology in their lives can help to achieve that in a more comprehensive manner. A better understanding of how this condition affects PWA's and their caregivers' QOL allows clinicians to target more specific interventions, and to develop programs for successful reintegration of these people in their community. This can also be an effective way of enhancing communication within family and provide PWA with a caring context for improving communication skills. According to social approaches, the aim of any intervention is to enhance QOL. Clinicians usually believe that their treatment will improve PWA and their families' and caregivers' QOL, however, a systematic measurement of QOL is needed to validate such a claim (Cranfill & Wright, 2010). Without this assessment, treatments may be considered successful despite poor psychosocial functioning or adjustment to the new life situation. Impairment-based assessments frequently contemplate language disorders, providing no information about the impact of the communication disability and treatment in patient's lives (Ross & Wertz, 2003). To achieve that, beyond the traditional assessments and interventions, more comprehensive assessments and interventions including social components are needed.

The consequences of aphasia are relatively well known, though the impact on their QOL has been less explored especially regarding PWA's caregivers. Moreover, despite the amount of

research regarding the effect of stroke in QOL, most studies have excluded PWA, since their language and communication problems restrict their participation in QOL assessment. To fill this gap, many efforts have been undertaken in the last decade to study PWA's QOL, but only few studies report on the significance of the impact of language and communication disability in QOL. In Portugal, little information is available about PWA's QOL (Rodrigues & Leal, 2013) and none is published yet about their caregivers QOL, so more research is needed to gain an empirically based understanding. Furthermore, to better understand the meaning of QOL scores, it is important to have population-based normative values (Wahl, Rustøen, Hanestad, Lerdal, & Moum, 2004). Since the normative values for Portuguese general population available are limited, our study began by collecting data from this population. Then, data was collected from PWA and their caregivers. The three groups were characterised regarding QOL and SR (since SR is a variable of concern in aphasia) and the results compared in order to study the impact of the communication disability in PWA and their caregivers' QOL. Correlated and predictive variables were identified.

CHAPTER 2: Literature review

2.1. Quality of life definition

Philosophers such as Plato and Aristotle were the first to discuss concepts related to QOL such as well-being, satisfaction and happiness (K. Anderson & Burckhardt, 1999; Martins, 2006). However, it was only after the Second World War that the concept of QOL became most widely used. First, it was applied when refering to material goods but in the 60's politicians began to use it to describe psychossocial satisfation and well-being (Martins, 2006; Pimentel, 2006). For instance, Cantril (1963) reported that in 1958 the major concerns of Americans were maintaining a satisfatory health and family life, a "decent" standard of living, housing and leisure as well as maintaining peace, continuing employment, working conditions, being accepted and having modern conveniences (Cantril, 1963). Later on Dalkey et al. (1972) identified different relevant categories for QOL: love; affection; self-respect and self-satisfaction; peace of mind; sexual satisfaction; stimulation and challenge; social acceptance; general achievement and job satisfaction; individuality; involvement and participation; comfort; economic well-being and good health; novelty and change: dominance; superiority; independence and privacy (Dalkey, Rourke, Lewis, & Snyder, 1972).

Through the years the population became more demanding and began to have broader goals related to life, happiness and well-being. The 80's positive psychology movement concerns about positive experiences of human existence had a great impact on organisations, and the client and patient satisfation became a crucial point to take into account in the strategical plan of the organisations (Claes, Hove, Loon, Vandevelde, & Schalok, 2010; Fleck, 2008). Also, the social indicators evolved, and currently the United Nations Development Programme encompasses social and education issues and is concerned with the impact of social and economic decision on the well-being of families and not merely with traditional economic indicators such as the incomes per capita (Fleck, 2008; WGISPC, 1996). Likewise, some changes happened in health. In 1948 WHO's definition of health covered domains such as physical, mental and social well-being and not simply the absence of disease (Fayers & Machin, 2007; Pimentel, 2006). The need to humanise health services increased and the relationship between the professional and the patient became more and more important and nowadays is recognised as having a large impact in treatment success (Fleck, 2008). All these issues influenced the concept of QOL. It evolved from a

material and biological point of view to aspects related to personal care, human rights, daily and social life as well as health issues (Martins, 2006).

According to Bowling's (1995) survey, the term QOL was only introduced by Medline as a heading in 1975 but a great interest in the subject in the medical literature started in 1970. There has been a proliferation of study groups, conferences, special journal issues and journals interested in general QOL such as the *Quality of Life Research* Journal (Bowling, 2001). According to O'Boyle (1997) there were only eight publications in which the term QOL was mentioned in Medline in 1974, but in 1996 the number increased to 1482 (O'Boyle, 1997). In 2005 there were about 69.000 citations (Moreno, Faerstein, Werneck, Lopes, & Chor, 2006).

Quality of Life is a multidimensional, and holistic construct that theoretically incorporates all aspects of an individual's life (Bowling, 2001; Pimentel, 2006). Its study has a longer tradition in the social and related sciences, although, currently, QOL is often used in many different fields for many different purposes. Since it is a broad and subjective concept, each discipline has promoted the development of different points of view of how QOL should be conceptualised and measured (Claes et al., 2010; Pimentel, 2006). For example, social scientists included factors such as socio-economic status, financial concerns, personal goals, employment and social support and, in some conceptualisations, spirituality, meaningfulness and beliefs are also included. Healthcare economists are concerned about resources allocation for the achievement of different goals focusing, for example, on cost-benefit relation. Health professionals devote great attention to illness and related variables, and more recently to functionality and social participation. The difficulty of identifying the components of QOL in both general population and in specific groups has also led to some problems in terms of defining the QOL concept (Holmes, 2005). To distinguish between QOL in such a general sense and the requirements of medicine and clinical trials, the concept of Health Related Quality of Life (HRQOL) emerged, concerned with the impact of a medical condition or treatment in one's physical, emotional and social well-being (Celia & Bonini, 1995; Fayers & Machin, 2007; Khanna & Tsevat, 2007)

Quality of life has been considered and defined in different ways which shows the difficulty in achieving an agreed meaning (Fayers & Machin, 2007; Phillips, 2006) and explains why it can be interpreted differently according to the discipline (Claes et al., 2010; Holmes, 2005; Phillips, 2006). As a result, there is more than one definition of QOL, and a large number of instruments to measure it (Claes et al., 2010; Pimentel, 2006).

It is currently accepted that the meaning of QOL should include all the significant areas that allow people to achieve their goals and to satisfy their needs at different levels; having the same

basic components for all people (Cummins, 2005; Fleck, 2008; Sorin-Peters, 2003; WHO, 1998). Thus, some common concepts and ideas about QOL emerged: it is subjective, since it is related to self-perception about one's performance (and should be enhanced by self-determination); and is multidimensional, i.e., comprehends various domains, including all the significant areas of life (physical functions and health, psychological status, level of independence, social relationships, relationship with environment, personal beliefs and spirituality) (Fleck, 2008; Sorin-Peters, 2003; WHO, 1998). The idea that basic components of QOL are the same to everyone suggests that there is an identifiable set of core domains common to all people, although they may vary in relative value and importance (Claes et al., 2010; Cummins, 2005). Individual variation exists because QOL depends on the fulfilment of life experience (Cummins, 2005; Fleck, 2008; Pimentel, 2006), but there are some basic common aspects (Cummins, 2005). It is important to study the common set of core domains but it is also important to study the variations according to certain variables.

Despite the diversity of definitions, that proposed by the World Health Organization (WHO) has gained greater consensus (Fleck, 2008; Worrall & Hickson, 2003). According to the WHO (1998), QOL is defined as the individual's perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. Subjects such as health, environment, family, work and culture are encompassed in QOL (WHO, 1998). In this study we will follow this QOL definition, which emphasises perceptions, and multiple dimensions and also reflects a complex, and integrative view of QOL (Gill et al., 2010).

2.2. Quality of life assessment

Quality of life is important for everyone and during a period of time it was believed that scientific, medical and technological advances would, by themselves, improve QOL (Verdugo, Schalock, Keith, & Stancliffe, 2005). For a long period of time science studied only the "dark side" of life, the disability, influenced by approaches such as the behaviourism in which anything subjective and not objectively observable was judged as unscientific (Lenderking, 2005). Currently it is accepted that life is influenced by complex combinations of the advances mentioned above, values, environment, expectations and perceptions (Verdugo et al., 2005; WHO, 1997). Furthermore, the increasing consumer empowerment and the emphasis in person-centred planning, contributed in large scale to increase the interest in studying QOL (Verdugo et al., 2005). In health, part of the development of research related to QOL results from concerns about health efficacy, efficiency or other economic concerns, but with the development of medicine and the increasing life expectancy, survival per se is no longer perceived as the main point of health, the goal is to enhance, restore or preserve QOL. Increasingly influenced by the ecological and social models, disability is progressively seen as part of the society and thus should be accommodated by it. Concerns about the impact of disability in individuals and their family increased and, thus, treating a disease in a pure biomedical framework is now widely recognised as insufficient (R. I. Brown, Schalock, & Brown, 2009; Fleck, 2008; Khanna & Tsevat, 2007; Moreno et al., 2006; Serra et al., 2006; Singh & Dixit, 2010). Such perspective influenced scientists to view all people as having the right to live with quality and that a key support goal is to enhance the QOL of the people and their families (R. I. Brown et al., 2009). Progressively more health care planners consider that assessing how people live their lives is crucial, recognising that measures of disease alone are insufficient determinants of health and life status, especially when it comes to chronic diseases, in which the main goal is to enhance functionality, to reduce the impact of the disability in the various areas of their lives, to maintain or to improve QOL (Fleck, 2008; Khanna & Tsevat, 2007).

2.2.1. Quality of life instruments

As QOL is a broad and subjective concept many instruments have been used to assess it, so there is no ideal measure, but some more suitable for a particular purpose (Cruice, Hirsch, Worrall, Holland, & Hickson, 2000; Cruice, Worrall, & Hickson, 2000; Opara & Jaracz, 2010; Skevington, Lofty, & O'Connel, 2004). The use of objective and subjective methodologies may be

important, nevertheless, there has been a preference for objective over subjective methods, thus reproducible data and standardised QOL instruments have been used more often (Cruice, Hirsch, et al., 2000; Cruice, Worrall, et al., 2000).

QOL instruments are conceptualised through a factor, facets and indicators structure (Claes et al., 2010; Cummins, 2005; Verdugo et al., 2005; WHO, 1997). The term *factor* is used to designate the higher order construct of QOL and is equivalent to the term *domain* (e.g., psychosocial). Quality of Life *domains* are the set of factors that define the multidimensionality of QOL (Claes et al., 2010; Cummins, 2005). The WHO (WHO, 1997) identified six main domains which describe core aspects of QOL cross-culturally: physical; psychosocial; level of independence; social relationships (SR); environment; and personal beliefs/spirituality. The WHO uses the *facet* concept which includes items of the same domain but dividing them in small subgroups of the same subject. For example, the SR domain of one WHO instrument has three facets: satisfaction with SR with others; support received from others; and sexual life (CPRO, 2007). *Indicators* are the perceptions, behaviours or conditions that define each domain, giving an indication of the person's well-being (e.g., social networks that characterise interpersonal relationships) (Claes et al., 2010; Verdugo et al., 2005). Indicators are sensitive to cultural and linguistic differences, and indicate variation and potential for improvement of outcomes (Verdugo et al., 2005). Indicators are items used to evaluate individual outcomes based on perceived well-being (self-report) or an objective indicator of the person's life experience based on direct observation (Claes et al., 2010).

Regarding health, there has been an on-going interest in developing patient-centred instruments that assess functional status and QOL (Fleck, 2008; Khanna & Tsevat, 2007; Patrick, 2008; Skevington et al., 2004; L. Williams, Weinberger, Harris, Clark, & Biller, 1999). The proliferation of measurement instruments reflects, in part at least, an increasing pressure to demonstrate the effectiveness of care and treatment and increasing consensus around the need to establish the effects of given illness or treatment on the patient's life and to incorporate the patient's perspective in evaluating interventions (Holmes, 2005). Consequently, there has been a multiplication of QOL measures, many of which were not based on a conceptual framework or lack cross-cultural equivalence (Canavarro et al., 2009).

Quality of life measures need to be robustly designed, tested and validated in order to be used. Therefore, it is essential that QOL tools are developed along robust procedures that include literature searching, consultation with expert groups, testing and psychometric properties analysis. QOL measures chosen in research studies should demonstrate reliability, validity, responsiveness to change over time, precision, appropriateness and acceptability of the

instruments (Buck, Jacoby, Massey, & Ford, 2000). Thus researchers should choose measures that have been developed this way such as the World Health Organization Quality of Life (WHOQOL) instruments (WHO, 1997).

QOL instruments can be considered to be generic or specific depending on their content. In health, generic instruments are designed to compare HRQOL across populations and diseases. They can be used as gold standards for overall QOL assessment so their results can be compared through different groups and individuals (Cummins, 2005; Khanna & Tsevat, 2007; Opara & Jaracz, 2010; L. Williams et al., 1999). They may inform and monitor outcomes, monitor people's health and estimate the burden of different conditions. This allows comparison across pathologies, levels of health and age ranges, however, the results cannot be directly comparable to those given by specific QOL instruments for disabled groups (Cummins, 2005). Otherwise, disease-specific instruments incorporate questions related to symptoms that are usually affected by specific diseases and are used to assess HRQOL in people in that specific condition (Khanna & Tsevat, 2007; Opara & Jaracz, 2010; L. Williams et al., 1999). Therefore, when using the instruments, it is crucial to know if they are adequate for the aim of the study (Opara & Jaracz, 2010). In this study different groups will be compared (general population, PWA and caregivers), so generic QOL instruments such as the WHOQOL are more appropriate. QOL measures can also embrace objective and subjective perspectives in rating (Cummins, 2005; Verdugo et al., 2005; WHO, 1997). Subjective information is typically ascertained through satisfaction or importance judgements made by the individual. Some QOL measures focus entirely on objective information, whilst others such as the WHOQOL instruments include subjective perspectives (WHO, 1997). Additionally, instruments typically measure QOL, HRQOL or well-being independently, but the WHOQOL instruments bridge the gap between them (Hawthorne, Davidson, et al., 2006).

A structured review made by Haywood, Garratt, and Fitzpatrick (2005) about generic self-assessed health instruments in older people based on 122 articles related to 15 different instruments revealed that the Short-Form General Health-36 (SF-36) was the most extensively used and that it had a good reliability, validity and responsiveness, followed by the Nottingham Health Profile (NHP) (Hunt, McKenna, McEwen, Williams, & Papp, 1981) and the EuroQol (EQ-5D) (EuroQolGroup, 1990). They also concluded that SF-36 is recommended when a detailed and broad ranging assessment of HRQOL is required, particularly in older people with lower levels of morbidity. The EQ-5D is recommended when a more succinct assessment of health status is required, particularly for patients in whom a substantial change in health is expected (Haywood et al., 2005).

Much of the psychometrics literature is based on studies of one instrument, however a small body of literature reports on psychometrics of two instruments or more in the same sample, which allows more awareness choices for the researchers. Willige, Wiersma, Nienhuis, and Jenner (2005) studied the suitability of EQ-5D and WHOQOL-Bref for psychiatric patients. According to their results EQ-5D is less sensitive to changes in social and psychological well-being than WHOQOL-Bref. The EQ-5D has been often used as an index in economic evaluations and thus, more suitable for that than to assess these patients' QOL (Willige et al., 2005). Unalan, Soyuer, Ozturk, and Mistik (2008) compared the suitability of SF-36 and the WHOQOL-100 for people with stroke (people with communication problems were excluded) and concluded that both instruments are useful in the practical evaluations of patients with stroke (Unalan et al., 2008), but Huang, Wu, and Frangakis (2006) observed that both instruments seem to measure different constructs: the WHOQOL-Bref measures overall QOL, including both health-related and non-health related QOL, whilst the SF-36 assesses aspects of health and activities generally affected by health conditions. Additionally, SF-36 is more focused in the objective QOL perceived states, while the WHOQOL-Bref is more focused in the self-perceived subjective QOL, which means that is focused in the satisfaction with these states (Huang et al., 2006). According to Veenhoven (2000) SF-36 is a measure of individual's internal capability of life and the WHOQOL a measure of inner life satisfaction or subjective enjoyment of life (Veenhoven, 2000). This means that the differences between the results in both instruments may reflect that individuals successfully adapt and cope with health problems, they may overcome the poor functioning or severity disability as measured by SF-36 and live a satisfying life as measured by the WHOQOL-Bref (Huang et al., 2006). Accordingly to these findings, the WHOQOL-Bref seems to be a reliable instrument to capture QOL in clinical populations.

As outlined above (Haywood et al., 2005), there are three popular measures of choice. The EQ-5D is available in many languages including EP, has 6 items that cover mobility, self-care, daily activities, pain/discomfort and anxiety/depression, and is brief to complete resulting in minimum respondent burden (Haywood et al., 2005). However, its brevity is a disadvantage in the context of this study where detailed information is desired on Portuguese population, PWA, and caregivers, and it has no item on SR which is a core concern to both PWA and caregivers. The SF-36 is considered a gold standard, is available in many languages and is more detailed with 36 items and 8 domains, however it has been proven to be difficult for people with aphasia to complete because of heavy linguistic and cognitive demands (Cruice, Hirsch, et al., 2000; Cruice, Worrall, & Hickson, 2010). The NHP is based on a "yes" or "no" answer-type which is very

restrictive considering the detail required for this study; additionally, according to Oliveira and Orsini (2008) the NHP is more a physical and emotional health measure, having some problems with the assessment of QOL, thus also not appropriate for this study.

Considering the fact that the use of WHOQOL instruments (WHOQOLGroup, 1993) have been increasing around the world, being also one of the most used instruments to assess QOL (CPRO, 2007; Huang et al., 2006; Khanna & Tsevat, 2007), and the advantages already presented on WHOQOL tools, these instruments will be discussed below.

2.2.1.1. World Health Organization quality of life instruments

A project was initiated in 1991 by the WHOQOL Group aiming to achieve an internationally-applicable and cross-culturally comparable instrument that assesses QOL. More than 30 centres were involved worldwide developing new national versions according to a standardised protocol (CPRO, 2007). The principles that guided the development of this instrument address the following criteria: it is a comprehensive instrument (includes all the domains and items considered essential); it is a subjective measure self-administered or interviewer assisted and includes subjective ratings of QOL since individuals' perception of QOL varies depending on their expectations (it is influenced by their adjustable internal standards); it is sensitive to the various domains of QOL (capable to show their relative importance); and it has cultural relevance and is cross-culturally comparable (CPRO, 2007). The WHOQOL instruments incorporate the subjective assessment approach alongside an objective tool, by including questions about the satisfaction that the individuals feel with their functioning, and how important it is for them. WHOQOL instruments also include the environment and the interactions between the people and the environment which were not studied when using other QOL assessments (Cruice, Worrall, et al., 2000; WHO, 1997). Two instruments have been created and these are discussed in turn below.

The WHOQOL-100 is an instrument representing 24 facets organised into six domains: physical; psychological; level of independence; SR; environment; and spiritual/religion/personal beliefs. It has four questions per facet with a total of 96 questions and four additional questions related to subjective aspects of global QOL and health. The 100 items reflect the questions considered important by specialists and people from general population. All answers are completed using a Likert scale. The WHOQOL-100 is cross-culturally applicable and is based on the individual's perceptions about their QOL in the last two weeks (CPRO, 2007; Khanna & Tsevat, 2007; Moreno et al., 2006).

The WHOQOL-100 is a comprehensive instrument, but takes a long time to complete. Therefore, a short version with 26 items has been developed, the WHOQOL-Bref (Khanna & Tsevat, 2007; Moreno et al., 2006). The WHOQOL-Bref has a four-domain structure: the physical domain is merged with the level of independence domain; and the psychological domain is merged with the spirituality, religion, and personal beliefs. The WHOQOL-Bref contains one item from each of the 24 facets of WHOQOL-100 and two additional items designed as indicators of overall QOL, which are "How would you rate your QOL?" and "How satisfied are you with your health?" (Hawthorne, Herrman, & Murphy, 2006; Khanna & Tsevat, 2007; Moreno et al., 2006). The conceptual and psychometric criteria were taken into account when Bref items were selected from the longer version. The comprehensive nature was preserved, the questions with the strongest item-total correlation were selected (Moreno et al., 2006), and psychometric and focus group procedures were used (CPRO, 2007). The WHOQOL-Bref is an instrument with items that can be adapted, added or withdrawn once demonstrated that it is a need for that population (CPRO, 2007; Hawthorne, Davidson, et al., 2006; Hawthorne, Herrman, et al., 2006). Thus, to ensure cultural sensitivity there are subtle differences between different countries/populations versions (Hawthorne, Herrman, et al., 2006). The Portuguese versions are equivalent to the standard versions (Canavarro et al., 2009; Serra et al., 2006).

In the specific case of WHOQOL, the focus groups and expert opinion from culturally and economically different countries represents an underlying common construct. It is therefore an instrument with high ecological validity. This cross-cultural perspective allows comparisons of diverse populations in various cultural settings and countries. In fact, the rigorous standards of instrument development used for the WHOQOL allow comparisons between cultures and also between different services or treatments and longitudinal studies of interventions with less risk of bias (Power, Quinn, Schmidt, & WHOQOLGroup, 2005; WHOQOLGroup, 1993).

The WHOQOL instruments are available in more than 40 languages (Huang et al., 2006), for example, the English and the European Portuguese versions of the WHOQOL-100, and the English, European Portuguese, Chinese, Czech, Farsi, Indonesian, Polish, Russian and Taiwan WHOQOL-Bref versions (Canavarro et al., 2009; Li, Young, Xiao, Zhou, & Zhou, 2004; Serra et al., 2006; Skevington et al., 2004; WHO, s.d.). Various studies from different countries have reported good psychometric properties of the WHOQOL-100 and the WHOQOL-Bref, and data is available for the Portuguese WHOQOL instruments (Canavarro et al., 2009; Chen et al., 2009; Fleck, Leal, et al., 1999; Fleck, Louzada, et al., 1999; Fleck et al., 2000; Ginieri-Coccossis et al., 2009; Huang et al., 2006; Kalfoss, Low, & Molzahn, 2008; Liang et al., 2009; Noerholm et al., 2004; Serra et al., 2006;

Usefy et al., 2010; Wang, Yao, Tsai, Wang, & Hsieh, 2006; Yao & Wu, 2009; Yao, Wu, & Yang, 2008).

Skevington et al. (2004) studied, 11830 adults from 24 different centres (23 different countries) who completed the WHOQOL-Bref. The results showed no evidence of ceiling and floor effects for any item and the Cronbach's alpha was good for all domains (0.80-0.82) except for SR which was acceptable (0.68) (the only three items of the SR domain may contribute for these results). For the majority of the countries, discriminant validity was significant for every domain in the total sample; and it was more evident in the physical domain, followed by the psychological, SR and environment. Item-total correlations showed generally good results (Skevington et al., 2004). According to these authors, future research should focus on more comprehensive global data collection, also using structured samples of patients (Skevington et al., 2004).

2.2.1.2. Stroke specific quality of life assessment

Some instruments have been widely used to measure the QOL of people with stroke (Jaracz & kozubsky, 2003; Kim, Warren, Madill, & Hadley, 1999; Kranciukaite & Rastenyte, 2006; Malheiro, Nicola, & Pereira, 2009) such as: the Stroke Adapted 30-item version of the Sickness Impact Profile (SA-SIP-30) (Straten, Haan, Limburg, & Bos, 2000); the Stroke version of Quality of Life Index (QLI) (Ferrans & Powers, 1985); the Stroke Impact Scale (SIS) (Duncan et al., 1999); and the Stroke Specific Quality of Life Scale (SS-QOL) (L. Williams et al., 1999). WHOQOL-Bref has also been shown to be suitable for people with stroke (Oliveira & Orsini, 2008). All the disease specific instruments mentioned above accommodate the stroke-specific aspects; the SA-SIP-30 and the SS-QOL include some items of social interaction, but they are focused on dysfunction and difficulties (Malheiro et al., 2009; Straten et al., 2000; L. Williams et al., 1999). This study is focused in importance and satisfaction with functioning, so these are not adequate instruments for this purpose. The stroke version of the QLI focus on importance and satisfaction, but is too long with its 72 items and only a few items are about SR (Kranciukaite & Rastenyte, 2006) which is a key concept for this study.

2.2.1.3. People's with aphasia quality of life assessment

Although a number of stroke-specific QOL scales have been developed, most exclude PWA and people with cognitive disabilities. In order to overcome this limitation, Hilari, Byng, Lamping, and Smith (2003) adapted the SS-QOL resulting in a specific interviewer-administered self-report

scale for PWA: the Stroke Aphasic Quality of Life Scale (SAQOL-53 and SAQOL-39). The longer version (SAQOL-53) has all the items of the SS-QOL plus four items related to difficulties with understanding speech, difficulties with making decisions and the impact of language problems on family and social life. These items were introduced to increase the content validity with this population. It has 12 domains based on the SS-QOL: self-care; mobility; upper extremity function; work; vision; language; thinking; personality; mood; energy; family; and social roles. The response format is based on a five-point Likert scale. The sample of this study (Hilari, Byng, et al., 2003), was composed of 74 people with mild to moderate aphasia and nine with severe aphasia, and showed that the shortest version (SAQOL-39) is likely to have better psychometric results. In SAQOL-39 the items are grouped in four domains: physical; psychosocial; communication; and energy (Hilari, Byng, et al., 2003).

There are some cultural adaptations of the SAQOL-39: Greek (Kartsona & Hilari, 2007); Brazilian Portuguese (Portero-McLellan, Rocha, Sakzenian, & Panhoca, 2009; Ribeiro, 2008); Spanish (Lata-Caneda, Piñeiro-Temprano, García-Armesto, Barruego-Egido, & Meijide-Failde, 2009); Italian (Posteraro et al., 2004; Posteraro et al., 2006); Dutch (A. Manders, Dammekens, Leemans, & Michiels, 2010); and European Portuguese (Rodrigues & Leal, 2013). The Portuguese version is very recent so it was not available when decisions were made on QOL measures for this study. Furthermore, it is focused in the difficulties people have doing things, so does not align with this study concerns.

Several other instruments such as the SF-36, the Dartmouth COOP Charts, the How I Feel About Myself Well-being Scale (Cruice, Worrall, Hickson, & Murison, 2003, 2005), the WHOQOL-Bref, the Psychosocial Well-being Index (PWI) (Ross & Wertz, 2002, 2003) and the Aachen Life Quality Inventory (ALQI) which is a German adaptation of the SIP specifically validated for brain-damaged patients after neurosurgical treatment (Engell, Hütter, Willmes, & Huber, 2003) have also been used to assess the QOL/HRQOL of PWA. According to Ross and Wertz (2003) PWI was less sensitive than the WHOQOL-Bref to differences in the QOL between people with and without aphasia and the SR was one domain that showed it.

Some studies (Cruice, Hill, Worrall, & Hickson, 2010; Cruice, Worrall, & Hickson, 2006) used open-ended questioning methods to capture PWA's QOL (asking PWA and/or their proxies) avoiding to limit the responses and, thus, enabling people to think and express every aspect considered important to them (Cruice, Hill, et al., 2010). In this study a robust standardised measure that efficiently captured data through many participants was needed so the interview method was inappropriate for its time and resource intensiveness.

There are a few studies that used the proxies of PWA and the SAQOL-39 (Cranfill & Wright, 2010; Hilari, Owen, & Farrely, 2007), the SF-36, the Dartmouth COOP Charts, or the How I Feel About Myself Well-being Scale (Cruice et al., 2005). Almost all data showed that proxies and practitioners tend to underestimate patient's QOL (Cranfill & Wright, 2010; Cruice et al., 2005; Hilari et al., 2007), so research has demonstrated that these tools should be completed by PWA themselves, thus others are not reliable as proxies or substitutes (Cranfill & Wright, 2010; Cruice et al., 2005; Hilari et al., 2007).

There are several instruments that capture QOL and some can be suitable to, at least, some PWA, but even a comprehensive instrument may neglect some constructs that are important to people's QOL, especially when in specific conditions such as aphasia. According to Ross and Wertz (2003) supplementary standardised items, considered as personally relevant, should be provided as a complement (Ross & Wertz, 2003) and regarding PWA, since SR are insufficiently represented in QOL instruments, instruments need to be adapted (Cruice, Hirsch, et al., 2000). Since no Portuguese QOL and aphasia instruments were available at the time this study began and once we decided to use a population based instrument, the WHOQOL-Bref that has only three items on its SR domain, it was decided to use the longer version of this domain from WHOQOL-100. Further detail on this decision will be given in methods section.

2.3. Quality of life of general population

A wide and deep review of the literature within health and outside health was undertaken in this chapter in order to have grounding for the investigation. The following databases were searched: Medline; Pubmed; Cochrane Library; B-on; PsyclNFO; and Web of Science. The references section of the papers were also examined to find more relevant literature. Grey literature was also consulted when considered relevant. The search was undertaken in English and Portuguese and the papers published in peer-reviewed journals were prioritised. This subsection includes a brief introduction, and then the studies are presented. The earliest published paper found considered relevant was included in the literature review and then followed chronological order. Whenever possible, the country, sample size, instruments used, and main results on overall QOL, QOL domains, and its relationships with variables such as age, gender or other relevant variables are presented. Afterwards, a summary of study's findings is presented.

There is a vast amount of literature about the QOL of general population (Bowling, 1995; Brajša-Žganec, Merkaš, & Šverko, 2011; Canavarro et al., 2009; Hawthorne, Herrman, et al., 2006; Hsieh, 2008; Saxena, Carlson, Billington, & Orley, 2001; Skevington et al., 2004; Spagnoli, Caetano, & Silva, 2012). Several published papers aim to study the psychometric properties of the instruments and/or aim to compare the results of general population QOL with those of other groups, such as unhealthy groups (thus some unhealthy groups data will be generally presented in this section) (Canavarro et al., 2009; Ginieri-Coccossis et al., 2009; Kalfoss et al., 2008; Molzahn, Skevington, Kalfoss, & Makaroff, 2010; Serra et al., 2006; Skevington et al., 2004). Having an integral and multidimensional view of the QOL of the general population will allow identifying and planning the adequate support needs and will be useful for the orientation of the activities carried out by healthcare service providers and to adjust health and community programs and policies.

The earliest published study found considered relevant was Farquhar's (1995). This study was carried out in London with 40 participants and aimed to identify individuals' view of the quality of their lives. The results showed that older people are willing and able to talk about this subject and that when they use the term QOL they are thinking about good and bad things in their lives. Using in-depth unstructured interviews, when asked to describe the quality of their lives, individuals spontaneously classified it with adjectives such as "good" or "bad" and explained why. Some of the oldest people referred that their lives had "no quality" and tended to describe their QOL with more negative terms than the younger ones. Those living in a semi-rural area were more likely to describe their QOL in a more positive way than those living in the inner city. Results showed that family relationships, social contacts, general health and functional status are valuable components of QOL (Farquhar, 1995).

In the study carried out with 2000 adult British individuals, Bowling (1995) concluded that 62% of the sample rated their lives as "very good" or "good". Individuals aged 55 and over were more likely to classify their life as "as good as can be". Females aged over 65 were more likely than men of the same age to report this. Single females aged 16 to 25 were more likely to rate their lives as "as good as can be" or as "very good" than single males; the inverse was observed for single males and females aged 25 to 45. In response to a generic question about the five most important things in their lives the first thing listed were relationships with family or other relatives, followed by their own health, other person's health and finances/standard of living/housing. Social life and leisure activities was also frequently mentioned (Bowling, 1995).

Fleck, Louzada, et al. (1999) used the WHOQOL-100 and concluded, from a study with 50 healthy people and 250 patients with mean age of 44 years, all from Brazil, that QOL in the first

group was higher in all domains and that the domains with the highest score for this group were level of independence and spirituality. The lower ones were environment and physical domain (Fleck, Louzada, et al., 1999).

Another Brazilian study (Fleck et al., 2000) used the WHOQOL-Bref in 50 healthy participants and 250 patients. Results showed that, within the four domains of WHOQOL-Bref, the highest scores in general population were for the physical domain and for the SR in the patients' group. The lowest ones were environment for general population and also environment and physical domain for the patients group. All the domains had better results in the general population than in the group of patients. When the content validity of the instrument was analysed, the domain which had weakest correlations with the others was SR. It is also the domain which did not enter in the multiple regression as a predictor of QOL; 44% of QOL was explained by the other three domains (Fleck et al., 2000).

Lloyd and Auld (2002) studied the role of leisure in determining QOL, whether it is influenced by placed-centred attributes such as urban parks, sporting and entertainment facilities and services, or by person centred factors such as sense of achievement, social interaction, individual's level of satisfaction with, and attitudes toward their leisure lifestyle. Using a sample composed by people from general population, the authors (Lloyd & Auld, 2002) concluded that leisure satisfaction and participation in leisure activities explained a significant proportion of the variation in QOL, contributing positively to QOL. People who engage in social activities more frequently and who are more satisfied with the psychological aspects of the leisure experience, presented higher levels of perceived QOL. Thus, person-centred leisure attributes have a greater influence in QOL than placed-centred indicators (Lloyd & Auld, 2002).

The WHOQOL Group published the results of a study that analysed the psychometric properties of the WHOQOL-Bref (Skevington et al., 2004). The sample consisted of 11830 subjects from 24 centres with an age range from 12 to 97 and mean age of 45 years. The findings support that all the domains are scored worst in unhealthy people than in healthy people and that also QOL is worse in the unhealthy group. In addition, the psychological and SR domains showed significant differences indicating that women have better SR but poorer psychological functioning than men. The mean domain ranges decrease with age and the greatest changes are in physical domain (Skevington et al., 2004).

Noerholm et al. (2004) published a study with normative data for the Danish general population. The sample was composed of 1101 subjects aged from 20 to 79 years who responded to WHOQOL-Bref. Analysis of the four domains indicated that the ones with widest ranges are the

physical domain followed by the environment. SR and psychological domains had an equal range. Analysing the data by gender, the authors (Noerholm et al., 2004) found that genders ranges were equal for all but two domains: psychological and SR domains, in which females gave more importance to SR than males.

The study of Arnold et al. (2004) examined the contribution of the physical, social and psychological functioning to overall QOL. A large number (1851) of healthy subjects from the Netherlands responded the Medical Outcome Study Short-Form General Health Survey (SF-20). The highest QOL mean was for social functioning, followed by the physical and, at least, the psychological functioning. The results of a regression analysis showed that psychological functioning had the strongest independent relation with overall QOL (Arnold et al., 2004).

Wahl et al. (2004) studied the QOL of 1893 Norwegians aged 19-81 years from general population using the Norwegian version of the Quality of Life Scale. They concluded that women reported higher QOL than men. Furthermore, gender was significantly associated with items such as relationship with parents, having and rearing children, relationship with close friends, helping and encouraging others, participating in public affairs, self-expression, socialising and entertainment. Individuals with higher levels of education reported higher QOL and education correlated significantly to material comforts, health, helping and encouraging others, participating in public affairs, learning, understanding oneself, work, self-expression, active recreation, and independence (women scored higher than men). Although no correlation was found between age and the total score of QOL, age correlated positively and significantly with material comforts, having and rearing children, relationship with spouse, participating in public affairs, and active recreation, and correlated negatively with learning. Marital status also influenced the QOL: married or cohabitant individuals reported higher scores and the separated men reported the lowest scores. The items less affected by marital status were self-expression, socialising, active recreation and independence. Occupational status also influenced QOL scores: unemployed individuals reported lower scores, which affected all items except for self-expression. In addition, respondents with health problems reported lower overall QOL and lower scores in all individual items, except for entertainment, than the healthy ones. Among all items, the highest level of satisfaction for the whole sample was found in material comforts, close relationships with spouse and close relationships with friends (Wahl et al., 2004).

L. Leung and Lee (2005) studied the effects of social support, leisure activities, internet activities and media use on 696 Hong-Kong citizens' perceived QOL. Social support was significantly correlated to QOL as well as the participation on community or religious activities.

People with higher levels of positive social interaction, affection and emotional and informational support showed higher scores in the Satisfaction with Life Scale (L. Leung & Lee, 2005) .

The survey of Hawthorne, Herrman, et al. (2006) was carried out with a random sample of Australian adults and the results showed that the overall scores of WHOQOL-Bref domains were, in a descending order: environment; physical; psychological; and SR. Concerning age and gender, females' score decline slightly in the physical domain between 20-59 years and declined more quickly afterward. Male physical health scores showed a progressive decline between 20-59 years, then a steeper decline between 50-59 and 60-69 years. In the psychological domain, female scores were reasonably stable across all age cohorts, which was also observed for males until the age of 79, and then there was a smoother decline. Female and male SR results were reasonably constant across ages, though, males scored three to five points lower than females. In general, the findings were consistent with other studies relating health and QOL: when health status declines, so does QOL (Hawthorne, Herrman, et al., 2006).

The findings of Wang et al. (2006) showed that in Taiwan adults (n=13083) there are only non-significant minor gender differences on the four WHOQOL-Bref domains. The older the patients, the less satisfaction they report in the psychological domain. Furthermore, more than 50 years olds reported considerably lower satisfaction in the physical subscale. Minor age difference exists in either the social or environment domains. People with higher education levels gave higher scores across the four subscales (Wang et al., 2006).

In Brazil, Moreno et al. (2006) found that, in a zero to 100 scale, the WHOQOL-Bref physical domain had the best scores (mean of 74) followed by the SR and the psychological domain (both with a mean of 70) and that environment had the lowest score (mean of 57). The overall QOL mean score was 70 and the results for the question about satisfaction with general health had a mean of 64 (Moreno et al., 2006).

Also in Brazil, Fleck, Chachamovich, and Trentini (2006) applied the WHOQOL-OLD module to 424 old adult (60-80 years), 33% of them unhealthy. The overall mean QOL score was 71 for the healthy group and as 58 for the unhealthy. All the facets scored higher in the healthy than in the unhealthy group. In a descending order, the scores for the healthy group were: sensory abilities (mean=79); past, present and future activities (mean=72); social participation (mean=71); intimacy (mean=70); autonomy (mean=70); death and dying (mean=65). For the unhealthy the results were: sensory abilities (mean=63); death and dying (mean=62); intimacy (mean=59); autonomy (mean=57); past, present and future activities (mean=56); social participation (mean=52). Furthermore, the findings showed statistically significant correlations between QOL

and depressive and hopelessness symptoms. Hence, the higher the hopelessness and depressive symptoms, the less the QOL domains scored (Fleck et al., 2006).

According to the results of a study carried out by Serra et al. (2006) with Portuguese people from general population (N=315) and unhealthy people (N=289), both older than 18 years, healthy people had statistical significant better scores then patients in all domains of the European-Portuguese version of the WHOQOL-Bref. The patients were recruited from psychiatry, gynaecology, rheumatology, orthopaedic/oncology hospital departments and health centres. In a descending order, the results of the domains for general population were: physical; psychological; SR; and environment. For patients it was: SR; psychological; environment; and physical. Social relationships had acceptable results in both groups, although, general population classified it lower than patients in relation to other domains. Within patients this domain had good results when comparing to other domains. Analysis of a multiple linear regression revealed that all the domains were good QOL predictors explaining 58% of total variation. These results support those obtained in a pilot study of WHOQOL-Bref in Portugal and in other centres. This study also revealed that there is a negative correlation between QOL and depressive symptoms (Serra et al., 2006).

Based on an extensive and critical review of literature on leisure and QOL from a global international perspective, Iwasaki (2007) concluded that leisure-like activities help to promote people's QOL. Being involved in leisure activities contributes to develop positive emotions, greater self-esteem, social and cultural connections, and well-being (Iwasaki, 2007).

Kalfoss et al. (2008) studied the suitability of the WHOQOL-Bref for Canadian and Norwegian older people. One hundred and ninety two (192) Canadian and 469 Norwegian subjects aged 60 to 95 years old (mean=74) were recruited. All the domains scored lower in the Norwegian sample. In a descending order, the mean results for the domains in the Norwegians were: environmental; SR; psychological; and physical domain. The results for the Canadians were quite different: environment; physical; psychological; and SR. The authors also found that the WHOQOL-Bref discriminates between healthy and unhealthy groups (Kalfoss et al., 2008).

According to M. Levasseur, Desrosiers, and Tribble (2008), the QLI scores decrease with more activity limitations in older adults, thus, reduced activity level seems to influence negatively the QOL. The level of participation in activities of daily living (ADL) and social roles, as well as the satisfaction with participation scores are also negatively associated to activity limitations.

Concerning happiness, the 34 years worth of American data collected by the General Social Survey and analysed by Robinson and Martin (2008), revealed that happy people engaged in significantly more social activities, religious participation, newspaper reading and watching TV.

In a study conducted in Portugal, with the same sample as Serra et al. (2006), but using the WHOQOL-100, QOL of general population was also found to be higher than patients' QOL (Canavarro et al., 2009). Also in this study, SR is well placed in the ranking of domains. In the healthy group it had the second highest score and in the patients group, it was the first. Environment (healthy participants) and physical domain (patients) had the lowest scores (Canavarro et al., 2009).

In the study of Molzahn et al. (2010) the relative importance of the facets of the WHOQOL-100 and the WHOQOL-OLD to older adults from 22 different countries, was analysed. The sample was composed of 7401 individuals who responded to the questionnaire in a self-administered or interviewed way. The mean age of the sample was 73 years. Results showed that all the facets were considered important, scoring over three in a five-point scale, except the sex satisfaction facet. The highest importance given by the older adults was attributed to the ability to perform ADL, to be healthy, to have sensory abilities and the ability to move around, to have freedom and independence. The least importance was given to sex life, chance to learn new skills and to the ability to participate in community activities. Comparing genders, women rated the importance of all domains higher than men, except for sex. Using a stepwise multiple regression that controlled the small influence of gender, age, and health status, the most important facets were having energy, being happy, having well-functioning senses, and being free from pain (Molzahn et al., 2010).

The study of Gameiro et al. (2010) included the same 315 individuals from Portuguese general population as Canavarro et al. (2009) and Serra et al. (2006), and analysed the influence of gender, marital status, educational level, socioeconomic status, and living place (rural versus city) in QOL domains. The instrument used was the WHOQOL-100. Results showed that men were more satisfied with the psychological domain than women. The opposite was observed for spirituality. Age correlated negatively with all the domains, except for spirituality that correlated positively, and significantly with physical, independence, SR, and spirituality. Regarding marital status, divorced/separated and widower individuals had significantly worse results in SR, environment and spirituality. Educational level seemed to influence QOL domains' results, since undergraduate and postgraduate degrees were associated with better QOL domains' results. Socioeconomic status was significantly associated to the following QOL domains: physical,

independency and environment. No significant statistical differences were observed regarding living place. Predictors were identified for each domain: physical domain was predicted by educational level and marital status (8%); psychological domain was predicted by gender and marital status (4%); independency was predicted by age, socioeconomical status, and marital status (8%); SR were predicted by age, marital status, and educational level (9%); Environment was predicted by socioeconomic status, and marital status (8%); and spirituality was predicted by age, gender, level of education, and marital status (7%). Overall, the percentages of total variance explained were very low (Gameiro et al., 2010).

The study of Brajša-Žganec et al. (2011) investigated how leisure activities contribute to subjective well-being according to gender and age, in a group of 4000 Croatian citizens aged more than 18 years. The Subjective Well-Being Scale (SWB) instrument and the Leisure Activities Scale were the instruments used. In these instruments, almost all activities involve the use of communication and/or language abilities. The results showed a good level of SWB (6.7 in a 10-point scale) with no differences between males and females, which uniformly declined with age for both genders. Participation in several leisure activities improved SWB of Croatians and diverse leisure activities seem to be associated to age and gender. “Family leisure activities” such as visiting friends and going to church significantly contributed to the improvement of SWB of men and women of all ages, as well as activities such as going to the theatre, reading books and attending concerts. All women aged from 18 to 60 years and men aged from 31 to 60 years who participated in active socialising and going out had higher levels of SWB. Visiting cultural events significantly contributed to SWB of people with more than 30 years (Brajša-Žganec et al., 2011).

Cruz, Polanczyk, Camey, Hoffmann, and Fleck (2011) published normative QOL data for people from Brazilian general population living in Porto Alegre using the WHOQOL-Bref. The sample was composed of 751 participants aged 20 to 64 years, 38% men and 62% women. The results showed that males scored higher than females in all QOL domains, as well as healthy people. People with the lowest number of years of education had worse domain scores’ than those with the highest education level. Additionally, younger people showed significantly better QOL, and people with lower socioeconomic status had worse QOL. The SR domain was the one with the best scores overall, followed by psychological, environment and physical domain. According to the subgroups studied, SR was the domain with the greatest satisfaction in all of them, and participants were less satisfied with the physical or environmental domains (Cruz et al., 2011).

To study the validity of the Subjective Happiness Scale (four-item scale), Spagnoli et al. (2012) used a sample of 1017 adults of Portuguese general population. The gold measure used was the Satisfaction with Life Scale (five-item scale). The results confirmed the validity of the instrument and showed that the whole sample perceived a moderate sense of subjective happiness. In general, the females registered the highest scores, although no significant differences were found among gender. The authors divided the sample in five groups according to age: 25-29 years; 30-34 years; 35-39 years; 40-44 years; 45-50 years. They found that the youngest and the oldest group presented the highest scores but that there were no significant differences between the age groups (Spagnoli et al., 2012).

Analysing all these studies, most of them involving European citizens, we can see that the general population usually classifies their QOL as moderate or good and that variables such as age, gender, health, education, marital status, living place, employment and emotional status influence the QOL of general population (Canavarro et al., 2009; Farquhar, 1995; Fleck et al., 2000; Gameiro et al., 2010; Hawthorne, Herrman, et al., 2006; Serra et al., 2006; Skevington et al., 2004; Wahl et al., 2004; Wang et al., 2006). The relation between the variables may differ from study to study according to the culture, and sample.

The areas of life most frequently referred to as important in the reviewed studies were: SR (for both general population and patients); activities and participation; physical; environment; and psychological. In Portugal, when using the WHOQOL-100, the SR were the second most scored domain by healthy people and the first one by patients (Canavarro et al., 2009). Using the WHOQOL-Bref, Portuguese healthy people scored the SR in third place (Serra et al., 2006).

In general, the QOL declines when age increases and the physical domain is the one that decreases the most (Gameiro et al., 2010; Hawthorne, Davidson, et al., 2006; Skevington et al., 2004). Females reveal better QOL than males, especially in the social domain but men scored the sex item higher than women (Hawthorne, Davidson, et al., 2006; Molzahn et al., 2010). Regarding education, people with higher levels of education reported higher levels of QOL (Gameiro et al., 2010; Wahl et al., 2004) and people living in rural areas described their QOL more positively than people living in the inner city (Farquhar, 1995). Being married or living with a companion was a status associated to better QOL, as well as being employed (Wahl et al., 2004). Having depressive symptoms was associated to lower levels of QOL (Fleck et al., 2006). Different studies also showed that patients reported different (lower) results of QOL when compared to healthy people (Canavarro et al., 2009; Fleck et al., 2000; Serra et al., 2006; Skevington et al., 2004; Wahl et al.,

2004), thus it is important to study the QOL of patients, especially those less studied, in order to understand the areas of life most affected and to develop strategies and treatments to enhance these domains and their overall QOL. This leads us to the purpose of the present study which is to study the QOL of a specific group (PWA). The variables identified in this section (age, gender, health, educational level, marital status, living place, employment and emotional status) are studied in this project.

2.4. Quality of life of people with stroke

Aphasia results mainly from stroke so QOL stroke studies may have important data to analyse. The search strategy for the stroke QOL studies was the same of the previous section, so databases were searched along with the references list of papers to find more relevant studies. The search was undertaken in English and Portuguese and the papers of peer-reviewed journals were prioritised. The earliest published paper found considered relevant was included in the literature review and then followed chronological order. This subsection includes a brief introduction and then the results of the studies are presented in tables according to sample characteristics, method and main findings. Studies with original data will be presented in tables, whilst systematic reviews will be presented in text format linking its results with those of our literature review.

The number of people who survive a stroke and live with its consequences is increasing (ACS, 2009; Man, Yip, Ko, Kwok, & Tsang, 2010; Tengs, Yu, & Luistro, 2001). Therefore, the concerns about QOL of these people have been increasing too, and many studies have been undertaken to investigate their QOL, life satisfaction and subjective well-being (Astrom, Asplund, & Astrom, 1992; Clarke, Marshall, Black, & Colantonio, 2002; Gargano, Reeves, & Investigators, 2007; Haan, Limburg, Van der Meulen, Jacobs, & Aaronson, 1995; Haley, Roth, Kissela, Perkins, & Howard, 2010; Jaracz & kozubsky, 2003; Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005; Kim et al., 1999; King, 1996; S. Levasseur, Green, & Talman, 2005; Mayo, Wood-Dauphinee, Robert, Durcan, & Carlton, 2002; Niemi, Laaksonen, Kotila, & Waltino, 1988; Patel et al., 2006; L. Williams et al., 1999). The characteristics, aims, and the main findings of the studies with original data examined are reported in the tables 1 and 2.

Table 1: Sample characteristics of stroke QOL studies

Study	Sample size	Stroke sample data				
		Gender	Age (years)	Time post-stroke	Respondents	Excluded people
Niemi et al. (1988)	46 (6 with aphasia)	19 Women 27 Men	Mean: 48	3 months and 4 years	People with stroke	Severe aphasia Dementia People that could not complete the questionnaires
Astrom et al. (1992)	50	17 Women 33 Men	Mean: 71	3 months and 3 years	People with stroke Close relative or friend (if necessary)	Severe aphasia Cognitive deficits
Haan et al. (1995)	44	211 Women 230 Men	Mean: 73	≥ 6 months	People with stroke Proxy (if necessary)	N.a.*
King (1996)	86	47 Women 39 Men	Mean: 63 Range: 23-88	1 to 3 years	People with stroke	Cognitive and language function inadequate to participate
Kim et al. (1999)	50	21 Women 29 Men	Mean: 75 Range: 63-86	12 to 36 months	People with stroke	People that could not complete the questionnaires Cognitive impairment Receptive and expressive aphasia
Clarke et al. (2002)	282 stroke 5056 without stroke	52 Women 230 Men	Mean: 76	N.a.*	People with stroke	Severe cognitive impairment Aphasia
Mayo et al. (2002)	434 stroke 486 without stroke	249 Women 187 Men	Mean: 69	≥ 6 months	People with stroke	N.a.*
Jaracz and kozubsky (2003)	72 stroke 110 without stroke	46 Women 26 Men	Mean: 65 Range: 33-85	6 months	People with stroke	Dementia Severe aphasia
Jonsson et al. (2005)	304 stroke 234 caregivers	123 Women 181 Men	Range: 17-96	4 and 16 months	People with stroke	People that could not complete the questionnaires
S. Levasseur et al. (2005)	46	13 Women 33 Men	Mean: 64 Range: 20-84	Mean: 7 months	People with stroke	People that could not complete the questionnaires
Kong and Yang (2006)	100	37 Women 63 Men	Range: 16-80	≥ 12 months	People with stroke	Severe stroke Significant aphasia Cognitive impairments
Patel et al. (2006)	342	N.a.*	N.a.*	1 and 3 years	People with stroke	People that could not complete the questionnaires
Martins (2006)	81	39 Women 42 Men	Mean=73.62 Range: 42-93	1 and 2 years	People with stroke informal caregiver (if necessary)	Severe communication disability

* Not available

Table 1: Sample characteristics of stroke QOL studies (continued)

Study	Sample size	Stroke sample data				
		Gender	Age (years)	Time post-stroke	Respondents	Excluded people
Gargano et al. (2007)	373	210 Women 163 Men	Mean: 64	3 months	People with stroke caregivers (if necessary)	N.a.*
Haley et al. (2010)	272 stroke 272 without stroke	139 Women 133 Men	Mean: 70 Range: 46-90	9 to 12 months	People with stroke	Inability to communicate in English

* Not available

The sample sizes of the studies were between 46 and 441 individuals (S. Levasseur et al., 2005; Niemi et al., 1988) with both genders, mainly with more than 6 months post stroke. Some studies used proxies when the included individuals could not complete the questionnaires (Astrom et al., 1992; Gargano et al., 2007; Haan et al., 1995; Martins, 2006), but the majority of the studies excluded people with communication problems such as aphasia (Astrom et al., 1992; Clarke et al., 2002; Haley et al., 2010; Jaracz & kozubsky, 2003; Jonsson et al., 2005; Kim et al., 1999; King, 1996; Kong & Yang, 2006; Martins, 2006; Niemi et al., 1988), so overall the findings do not reflect PWA's living experience. These study's characteristics are in accordance with Kranciukaite and Rastenyte's (2006) stroke and QOL systematic review findings.

Table 2: Aims and main findings of the stroke QOL studies

Study	Aims	Methodology	Main findings
Niemi et al. (1988)	Determine the QOL of stroke survivors	Longitudinal Assessments at: 3M, and 4Y	QOL was not re-established in 83% of the stroke patients Most affected domain: leisure time activities People who did not return to work had worse QOL Oldest patients had worse QOL, especially for leisure time activities Men had slightly worse QOL than women, especially in leisure activities Motor impairment influences QOL No differences between PWA and others People that restored or improved QOL had higher scores for intelligence and memory Stronger predictor of QOL: depression, difficulties in ambulation, independency in daily living activities and memory Stroke impacts on QOL People with stroke need encouragement, psychosocial support and adjustment training after stroke

Table 2: Aims and main findings of the stroke QOL studies (continued)

Study	Aims	Methodology	Main findings
Astrom et al. (1992)	To describe different aspects of psychosocial function after stroke and the development of changes over time	Longitudinal Assessments at: 3M, 1Y, 2Y, and 3Y	At 3 months social contacts reduced At 1 year social contacts with friends improved but maintained lower than in general population 3 years after stroke people had more psychiatric symptoms, lower functional ability, and lower life satisfaction
	To identify mental, functional, and social factors associated with low life satisfaction late after stroke		Older people, more depressive symptoms, people that lived alone, that were less independent, that had fewer contacts had worse QOL Life satisfaction lower results were at 3 months, wherein 32% classified as "good"; at 1 year it increased for 52% People that reported poor life satisfaction at 1 year maintained it for the 3 years
Haan et al. (1995)	To analyse the impact of stroke types and lesion locations on QOL	Cross-sectional	High levels of dysfunction in body self-care, communication, eating household, management and ambulation were reported Less severe dysfunctions: sleep, emotional behavior and social interaction Physical and psychosocial functioning were worse than in general population Relationship between QOL and comorbidity, stroke severity and supratentorial stroke type Left hemisphere lesions had better results in all domains except for communication Oldest had worse results in physical and psychosocial domains No relationship between QOL and gender
King (1996)	To examine overall and domain-specific QOL in stroke survivors To identify variables that predict QOL after stroke	Cross-sectional	QOL similar to general population QOL predictors: depression, perceived social support and functional status Ability to communicate has great importance for life
Kim et al. (1999)	To describe the overall QOL of stroke survivors To examine the relationships between sociodemographic variables, neurological variables, functional status, social support, perceived health status, depression, and overall QOL To determine the best predictors of QOL	Cross-sectional	Health and functioning had the lowest results Important items 3 years after stroke: ability to get around, ability to do things, not having a job, usefulness to others and stress - all with lower levels of satisfaction Lower level of satisfaction with leisure time activities Depression is negatively associated to QOL Being married, perceived adequate social support from a close personal relationship is positively correlated with overall QOL Age, gender, education, living arrangements, stroke type and lesion location did not correlate significantly with QOL
Clarke et al. (2002)	To investigate patterns of well-being in community-dwelling stroke survivors To identify factors that restrict and enhance well-being	Cross-sectional	People with stroke had lower levels of well-being, particularly in their sense of mastery and control over their lives, and their ability to engage in positive relationships People with stroke are more likely to experience restrictions on their ADL Cognitive impairment limits sense of purpose and meaning Depression limits sense of mastery and acceptance Mental health, physical and cognitive impairment associated to reduced sense of well-being in people with stroke Higher levels of education and/or adequate social support can moderate stroke impact

Table 2: Aims and main findings of the stroke QOL studies (continued)

Study	Aims	Methodology	Main findings
Mayo et al. (2002)	To estimate the extent of activity and participation of individuals 6 months post stroke and their influence on HRQOL and overall QOL	Cross-sectional	Participation in ADL is associated to better QOL Stroke people report lack of meaningful activities
Jaracz and Kozubski (2003)	To describe global and domain-specific after stroke QOL To identify the factors that are important for post-stroke QOL	Cross-sectional	QOL relatively good for stroke survivors People with stroke had lower overall QOL and lower results in all domains Health and functioning had the lowest results Speaking and moving are perceived as the most important Family was the most scored dimension Emotional support, depressive symptoms and functional disability predicted QOL (explained 38%)
Jonsson et al. (2005)	To examine longitudinal changes of QOL covering physical and mental factors in a group of stroke patients and their informal caregivers	Longitudinal Assessments at 4 and 16 months	Caregiver had better QOL than patients except for emotional and mental domains Social, emotional and mental domains improved in patients Physical functioning decreased in patients There were no changes in caregivers QOL QOL determinants in patients at 16 months: depressive symptoms, functional status, age and gender
Levasseur et al. (2005)	To examine the applicability and construct validity of the SEIQoL-Direct Weight for measuring QOL in stroke survivors	Cross-sectional	Relationships with family and friends is the most important domain Social and leisure activities and health follow social relationships Perceived health status is associated to depressive symptoms
Kong and Yang (2006)	To assess HRQOL among chronic stroke survivors and factors associated with it	Cross-sectional	Age, gender, post-stroke duration, side of hemiplegia and Barthel Index (BI) results were not associated to HRQOL Depression was associated to HRQOL QOL comparable to general population except for physical functioning
Patel et al. (2006)	To estimate levels of disability, handicap and HRQOL up to 3 years after stroke To examine the relationships between domains	Longitudinal	Positive correlation between HRQOL and disability and handicap Disability is strongly correlated to HRQOL in physical functioning and moderate for social functioning Up to 3 years patients perceptions of physical health is low but mental health is satisfactory
Martins (2006)	To assess the QOL of people with stroke	Longitudinal	Low results in all QOL domains Ability to use the affected member, ability to participate in social and spiritual activities, ability to work and to participate in ADL were the lowest scored domains No significant differences in QOL perceptions between males and females Communication significantly decreased from 1 to 2 years post-stroke Communication correlated with memory and participation in ADL Age is negatively and significantly correlated with QOL at 1 and 2 years post-stroke Emotional status is not correlated with QOL Dependent individuals had worse QOL Individuals with more neurological deficits had worse QOL Stroke type had no correlation with QOL Marital status had no correlation with QOL

Table 2: Aims and main findings of the stroke QOL studies (continued)

Study	Aims	Methodology	Main findings
Gargano et al. (2007)	To examine sex differences in stroke survivors QOL	Cross-sectional	Females had lower mood score than males Women feel less satisfied with their level of memory and concentration Women had lower functional recovery Women had lower levels of QOL Age, stroke type or comorbidities do not explain the findings
Haley et al. (2010)	To measure the impact of stroke on QOL To analyze whether race, gender, age, or living alone moderated changes in QOL	Longitudinal	Stroke had negative effects on QOL, depression, mental health and physical health Living alone/social isolation is a risk factor for worse QOL, and for developing depressive symptoms No race and gender differences in QOL results

In the studies reported above we can observe that stroke survivors have worse QOL after stroke (Astrom et al., 1992; Clarke et al., 2002; Haley et al., 2010; Jaracz & kozubsky, 2003; Kim et al., 1999; Martins, 2006; Niemi et al., 1988). The same was found by Oliveira and Orsini (2008), Mota and Nicolato (2008), and Kranciukaite and Rastenyte (2006) in their systematic reviews. Stroke limits the participation in ADL, the engagement in SR, the functional status and the emotional and mental health (Clarke et al., 2002; Haley et al., 2010; Jaracz & kozubsky, 2003; Kranciukaite & Rastenyte, 2006; S. Levasseur et al., 2005; Martins, 2006; Mayo et al., 2002; Niemi et al., 1988; Oliveira & Orsini, 2008; Patel et al., 2006). As shown, depressive symptoms, disability, participation in ADL correlate significantly with QOL (Haan et al., 1995; Jaracz & kozubsky, 2003; Jonsson et al., 2005; Kim et al., 1999; King, 1996; Kong & Yang, 2006; Patel et al., 2006) and the maintenance or re-establishment of social ties seems to be an important determinant of QOL in long term survivors of stroke (Kranciukaite & Rastenyte, 2006); the importance that people gave to the SR support these findings (Jaracz & kozubsky, 2003; S. Levasseur et al., 2005). Likewise in Mota and Nicolato's (1995) review, some studies identified age and gender as determinant aspects for people with stroke's QOL (Gargano et al., 2007; Jonsson et al., 2005), but Haley et al. (2010), for instance, found no differences between gender. Haan et al. (1995) also found an association with stroke severity. Additionally, Kranciukaite and Rastenyte (2006) verified that the severity of motor impairment, incapacity to return to work, impaired cognition and the presence of comorbid health problems contribute to the reduction of QOL in stroke individuals. Some of the studies of this literature review also observed these results (Jaracz & kozubsky, 2003; Niemi et al., 1988; Patel et al., 2006).

Through a systematic review method, Tengs et al. (2001) concluded that there is a large variation in the instruments used to assess QOL for the same health condition and a considerable variation in the rigor of methods used to estimate QOL, which may hinder reliable

comparisons. Although not reported in the tables above, the mentioned studies used different instruments to assess QOL and correlated variables, e.g. SF-36, QLI, and SS-QOL (Gargano et al., 2007; Jonsson et al., 2005; King, 1996; Kong & Yang, 2006). The use of core instruments is desirable, so the QOL studies may contribute with reliable data about the impact of stroke in patients' QOL and might strongly influence the investment in stroke prevention and treatment relative to other conditions (Oliveira & Orsini, 2008; Tengs et al., 2001).

2.5. Quality of life of people with aphasia

The search strategy for this section was the same of the previous two, so databases were searched along with the references list of the papers to find more relevant studies. The search was undertaken in English and Portuguese and the papers of peer-reviewed journals were prioritised but grey literature was also considered when reporting Portuguese or Brazilian data. The earliest paper found considered relevant was included in the literature review and then followed chronological order. Therapy studies were not included. As in the previous section, it includes an introduction and results from all studies are presented in tables according to sample characteristics, method and main findings.

Aphasia is an acquired communication disorder caused by neurological damage characterised by a multimodal language impairment which may include speaking, understanding, reading and writing. It cannot be explained by motor or sensory deficit as well as intellectual deficit or psychiatric disorder (Goodglass, 1993; Hallowell & Chapey, 2008). There are many aphasia classifications. The most widely used is based on lesion location and language impairment including speech fluency, naming, auditory comprehension and repetition, which classifies aphasia as (Goodglass & Kaplan, 1972): Broca's aphasia; Wernicke's aphasia; conduction aphasia; anomic aphasia; global aphasia; transcortical sensory aphasia; transcortical motor aphasia and transcortical mixed aphasia(Goodglass & Kaplan, 1972). This is the classification used in this Thesis.

As a chronic acquired communication disorder, most people who suffer from aphasia see their lives changed forever. Changes occur at a linguistic and communicative level but also at different levels of daily living and QOL (Cruice et al., 2006; LaPointe, 2005; A. Manders et al., 2010; Pound, Parr, Lindsay, & Woolf, 2000). Aphasia affects the biopsychosocial integrity of the

individuals compromising the participation in ADL, in social activities, the ability to work, and their emotional status (LaPointe, 2005; Michallet, Tétreault, & Dorze, 2003; Pound et al., 2000; Zemva, 1999). The changes may involve the loss of communicative partners, participation in less activities, role changes, social isolation, dependency, and the development of depressive symptoms (Ardila, 2006; Berthier, 2005; Grawburg et al., 2013a; Jordan & Kaiser, 1996; Patrício, 2007; Währborg, 1991). To face all the changes, the psychosocial adjustment of the PWA and their families is very important (Cruice et al., 2006; Peña-Casanova, Manero, & Bertran-Serra, 1995).

The communicative condition of PWA is a methodological challenge in the area of QOL studies because they may have difficulties completing self-reported instruments. In fact, self-reported instruments are generally less suitable for people with moderate to severe cognitive disorders and speech and language disorders. In many studies of QOL of people with stroke, PWA were excluded (see section 2.4.), in some it is not clear whether they were included or not and in studies that did include PWA, those with moderate to severe aphasia were excluded or resulted in missed assessments. Some studies have therefore resorted to proxy respondents (Sarno, 1997), however QOL is quite a subjective concept, so the use of proxies is questionable. Statistical significant differences among PWA's responses and those given by the proxies have been reported, with PWA perceiving their QOL better than proxies (Cranfill & Wright, 2010; Cruice et al., 2005; Hilari et al., 2007), so the method of capturing QOL thorough proxies seems to be restrictive and unreliable. Thus eliciting information from PWA directly is preferable, as previously mentioned. To assess people with severe aphasia QOL, it is required, at least, some modification of the testing materials and special skills on behalf of the interviewer.

Improving the QOL of PWA is the ultimate goal of the clinicians who work with PWA (Worrall & Holland, 2003). Usually clinicians believe that when language and communication improve, QOL also increases. Nevertheless, it is necessary to determine the extent of the impact of aphasia in people's lives as well as the benefits of rehabilitation on their QOL (Cruice et al., 2003; Worrall & Holland, 2003). Enquiring the person about this is essential for a good practitioner care and to inform management (Cruice et al., 2006). Despite the available research on language impairment and communication disabilities, only a few studies have looked at tested proven relationships among language impairment, communication ability and QOL outcomes in PWA (Cruice et al., 2003; Hilari, Needle, & Harrison, 2012; Ross & Wertz, 2002). A review of QOL literature (Cruice, Worrall, et al., 2000) suggested that communication had not been investigated as predictor or factor that may influence QOL most probably because of its implicitness.

Consequently, there is a very limited research on statistical significance of how communication disability significantly influences people's QOL (Cruice et al., 2003; Hilari et al., 2012). The studies found in our literature review are presented in tables 3 and 4.

Table 3: Sample characteristics of PWA QOL studies

Study	Sample size	PWA sample characteristics				
		Gender	Age (Years)	Time post-stroke	Included people	Respondents
Hinckley (1998)	31 PWA	12 Women 19 Men	Mean: 50 Range: 23-69	Mean: 46 months ≥11 months	Fluent and non-fluent Mild, moderate and severe	PWA
Zemva (1999)	20 PWA 20 Relatives	5 Women 15 Men	Mean: 68 Range: 57-82	Range: 1-48 months	20 Broca	PWA
Ross and Wertz (2002)	18 PWA 18 Non-brain injured	5 Women 13 Men	Mean: 61 Range: 41-79	Mean: 43 months ≥ 6 months	5 Anomic 4 Conduction 3 Broca 2 Wernicke 4 Residual	PWA Interviewer assistance if necessary
Engell et al. (2003)	26 PWA 24 Partners	9 Women 17 Men	Mean: 54 Range: 26-69	Mean: 12 months Range: 1-63 months	8 Global 6 Broca 1 Wernicke 1 Transcortical sensory 1 Amnesic 2 Residual 4 Fluent non-classifiable 3 Non-fluent non-classifiable	PWA
Cruice et al. (2003)	30 PWA	16 Women 14 Men	Mean: 71 Range: 57-88	Mean: 41 months Range: 10-108 months	Mild to moderate 15 Anomic 8 Conduction 3 Broca 3 Wernicke 1 Transcortical sensory	PWA
Ross and Wertz (2003)	18 PWA 18 Non-brain injured	5 Women 13 Men	Mean: 61 Range: 41-79	Mean: 43 months ≥ 6 months	5 Anomic 4 Conduction 3 Broca 2 Wernicke 4 Residual	PWA Interviewer assistance if necessary
Hilari et al. (2003)	83 PWA	31 Women 52 Men	Mean: 62 Range: 21-92	≥1 year	N.a.*	PWA

*Not available

Table 3: Sample characteristics of PWA QOL studies (continued)

Study	Sample size	PWA sample characteristics				
		Gender	Age (Years)	Time post-stroke	Included people	Respondents
Cruice et al. (2006)	4 PWA 4 Significant others	4 Women	Mean: 59 Range: 68-81	Range: 1-4 years	N.a.*	PWA
Ribeiro (2008)**	30 PWA 30 General population	16 Women 14 Men	N.a.*	≥6 months	4 Anomic 14 Broca 6 Conduction 6 Mixed	PWA
Bose et al. (2009)	19 PWA 19 Controls	5 Women 14 Men	Mean: 65 Range: 27-79	Mean: 42 months Range: 8-155 months	5 Anomic 7 Broca 2 Global 2 Wernicke 3 Mixed aphasia	PWA
Lata-Caneda et al. (2009)	23 PWA	7 Women 16 Men	Mean: 57 Range: 42-74	Mean: 44 months ≥ 11 months	9 Broca 1 Wernicke 5 Transcortical motor 3 Transcortical sensory 1 Anomic 4 Global	PWA
Manders et al. (2010)	43 PWA 43 Brain injured 43 Healthy	18 Women 25 Men	Mean: 62 Range: 35-85	Mean: 4 months	Good to moderate comprehension	PWA
Cruice, Hill et al. (2010)	30	16 Women 14 Men	Mean: 71 Range: 57-88	Mean: 41 months Range: 10-108 months	15 Anomic 8 Conduction 3 Broca 3 Wernicke 1 Transcortical sensory	PWA
Cruice, Worrall et al. (2010)	30 PWA 75 Without aphasia	16 Women 14 Men	≥ 57	≥ 10 months	Moderate comprehension	PWA
Rodrigues and Leal (2013)	33 PWA	16 Women 17 Men	Mean: 67.5 Range: 49-86	Mean: 32 months Range: 11-120 months	5 Global 9 Broca 10 Anomic 2 Wernicke 5 Conduction 1 Transcortical motor 1 Transcortical sensory	PWA

*Not available
**Grey literature

The sample sizes of the studies reviewed were between 4 and 83 PWA (Cruice et al., 2006; Hilari, Wiggins, Roy, Byng, & Smith, 2003) of both genders, but the majority of the studies had a sample size between 20 and 30 participants (Bose, McHugh, Schollenberger, & Buchanan, 2009;

Cruice, Hill, et al., 2010; Cruice, Worrall, et al., 2010; Cruice et al., 2003; Engell et al., 2003; Lata-Caneda et al., 2009; Ribeiro, 2008; Ross & Wertz, 2002, 2003; Zemva, 1999). The great majority had more than 6 months post stroke and the age range was of 21 to 88 years (Bose et al., 2009; Cruice, Hill, et al., 2010; Cruice et al., 2006; Cruice, Worrall, et al., 2010; Cruice et al., 2003; Hilari, Wiggins, et al., 2003; Hinckley, 1998; Lata-Caneda et al., 2009; Ribeiro, 2008; Rodrigues & Leal, 2013; Ross & Wertz, 2002, 2003). Interviewer assistance was given if necessary in some studies (Ross & Wertz, 2002, 2003).

Table 4: Aims, methodology and main findings of PWA QOL studies

Study	Aims	QOL instrument	Methodology	Main findings
Zemva (1999)	To establish handicaps most commonly occurring in the life of aphasic patients and their relatives	Interview	Cross-sectional	PWA were more troubled by their communication disability than their relatives PWA reported changes in family and social life and at emotional level Turning to wishes, PWA prioritised communication, to be able to speak, complete recovery
Hinckley (1998)	To investigate the predictors of lifestyle satisfaction among younger adults with chronic aphasia	Questionnaire designed for the study	Cross-sectional	45% rated life satisfaction as positive 54% were dissatisfied or discourage with their lifestyle Only time post-onset was a significant predictor of lifestyle satisfaction As time post-onset increases the satisfaction decreases
Ross & Wertz (2002)	To examine relationships between language and/or communication deficits and QOL To determine whether the strengths of these relationships differ between groups	WHOQOL-Bref PWI	Cross-sectional	PWA scored significantly lower on all measures No significant association between severity of language disability and QOL of PWA No significant relationships were verified between communication activity limitation and QOL
Engell et al. (2003)	To construct and validate a procedure that would allow for self-rating of aphasic patients	Aachen Life Quality Inventory	Cross-sectional	No significant relationship between QOL and gender No significant relationship between QOL and educational level No significant relationship between QOL and time post stroke Language impairment was correlated to QOL Non-fluent individuals complaint more than fluent
Cruice et al. (2003)	To investigate how measures of impairment, activity and participation, and measures of QOL related to each other for PWA	SF-36 Dartmouth COOP Charts Well-Being Scale	Cross-sectional	Strong positive correlation between communication and: social HRQOL; and psychological well-being Emotional and functional limitation correlate with lower QOL

Table 4: Aims, methodology and main findings of PWA QOL studies (continued)

Study	Aims	QOL instrument	Methodology	Main findings
Ross and Wertz (2003)	To determine which WHOQOL-Bref facets differentiate QOL between aphasic and non-aphasic people	WHOQOL-Bref PWI	Cross-sectional	PWA had lower QOL The domains which discriminate most powerfully the QOL of aphasic and non-aphasic people are the level of independence, SR and environment Within SR domain, respondents' satisfaction with support received from friends and with their sex lives best distinguish QOL between groups Results suggest that aphasic people may benefit from language therapy to enhance communication for specific situations and to reinforce the participation in society
Hilari et al. (2003)	To assess the predictors of HRQOL in PWA	SAQOL-39	Cross-sectional	Age was significantly and negatively correlated to QOL Time post-stroke and type of stroke were not correlated to QOL Comorbidity was correlated to QOL; more comorbid conditions resulted in poorer QOL High emotional distress was significantly and positively correlated with QOL Lower level of activities was significantly and positively correlated with QOL High communication disability was significantly and positively correlated with QOL Low cognitive level was significantly and positively correlated with QOL Social support was positively but not significantly correlated with QOL Multiple regression analyses of these variables and QOL revealed that only emotional distress, activity level, communication disability and comorbidity were significant predictors of QOL, accounting for 52% of the variance of the SAQOL-39 results
Cruice et al. (2006)	To explore how older PWA consider the quality of their current lives	Interview	Cross-sectional	Contributors for successful living: having positive experiences in sharing one´s life with others; visiting family; socialising, playing with grandchildren; sharing tasks Other important aspects for satisfaction with life: be oneself; having support; having independence (being able to: live alone; travel independently; do things they want to do; to manage one's responsibilities) Better sense of QOL was noticed comparing to a time immediately post-stroke
Ribeiro (2008)**	To translate and adapt the SAQOL-39 To verify its suitability for PWA	SAQOL-39	Cross-sectional	Gender, educational level, and time post stroke had no correlation with QOL Age had a positive correlation with QOL The participants with aphasia revealed lower results in all SAQOL-39 domains comparing to the control group

**Grey literature

Table 4: Aims, methodology and main findings of PWA QOL studies (continued)

Study	Aims	QOL instrument	Methodology	Main findings
Bose et al. (2009)	To document the domains of QOL that were most affected for participants with aphasia compared to control participants	SAQOL-39 17-item Quality of Communication Life Scale (QCL)	Cross-sectional	PWA had significantly lower QOL scores While controls showed similar values in all subdomains of SAQOL and QCL, the PWA had different performances across the domains, with communication and socialization/activities being the most affected domain Aphasia severity strongly correlated with communication and psychosocial subdomains of SAQOL as well as with socialization/activities subdomain of QCL Naming performance correlated strongly with psychosocial domain and socialization/activities and to aphasia severity Age, level of education and time post stroke did not correlate with any studied variable
Lata-Caneda et al. (2009)	To translate the SAQOL-39 to Spanish and evaluate its acceptability and reliability	SAQOL-39	Cross-sectional	Mean score for QOL was 3.75 (range: 2.06 to 4.94) Lowest mean score was for the communication domain 3.29 (1.57-5), followed by the psychosocial domain 3.67 (1.63-5), the energy domain 3.98 (1-5) and the physical domain 4.05 (2.40-5)
Manders et al. (2010)	To examine the QOL of PWA To study the influence of age, time post onset and social support on the QOL of PWA	SAQOL-39 (not validated version)	Cross-sectional	Significant differences between PWA and the healthy control sample for overall QOL and for all domains A comparison between both groups with brain injury showed no differences on the physical and energy domains, but revealed significant differences for communication and psychosocial domains and for the total SAQOL-score PWA had the lowest results in overall QOL and in all QOL domains of SAQOL, except the physical one People who had aphasia for a longer time tended to have better QOL Females with aphasia tend to evaluate their QOL more negatively than males revealing significant differences for the physical and psychosocial domain as well as for the total SAQOL-score Aphasic people who have not finished high school scored significantly lower in physical domain and in overall QOL No significant differences were found regarding to marital status PWA who were older than 65 years scored significantly lower than the younger group.
Cruice, Hill et al. (2010)	To explore how older people with chronic aphasia who are living in the community describe their QOL in terms of what contributes to and detracts from the quality in their current and future lives	Interview	Cross-sectional	Factors that influence QOL: Activities (previous occupation, personal interests, entertainment, social activities) Verbal communication (speaking to others, going to discussion groups, lack of ability to talk or speak) People (having partners, family and other people in their lives) Body functioning (current physical difficulties, cognitive and sensory functioning)

Table 4: Aims, methodology and main findings of PWA QOL studies (continued)

Study	Aims	QOL instrument	Methodology	Main findings
Cruice, Worrall et al. (2010)	To verify the suitability of the SF-36 for aphasia To report on the impact of post-stroke aphasia in HRQOL	SF-36	Cross-sectional	PWA had significantly lower emotional and mental health PWA with depressive symptoms had lower HRQOL than PWA without those symptoms SF-36 is not advisable for adult PWA
Rodrigues & Leal (2013)	To translate and analyze the psychometric properties of the Portuguese version of the SAQOL-39	SAQOL-39	Cross-sectional	Communication domain had the lowest scores Communication domain was not associated to time post-stroke Age, gender, educational level did not correlate with QOL Time post-stroke is associated to QOL, especially with the physical domain

The results of various studies revealed that PWA have lower scores of QOL than people without aphasia (A. Manders et al., 2010; Ribeiro, 2008; Ross & Wertz, 2002, 2003). Emotional status and age seems to be the strongest predictors of PWA's QOL (Bose et al., 2009; Cruice, Worrall, et al., 2010; Cruice et al., 2003; Hilari, Wiggins, et al., 2003; A. Manders et al., 2010; Ribeiro, 2008), but Rodrigues and Leal (2013) did not find the age association in a Portuguese sample. Communication and psychosocial QOL domains were those that better discriminated people with and without aphasia (Bose et al., 2009; Hilari, Wiggins, et al., 2003; A. Manders et al., 2010; Ross & Wertz, 2003). There is also a strong correlation between communication and social HRQOL, psychological well-being and QOL (Cruice et al., 2003; Hilari, Wiggins, et al., 2003). Greater importance was given by PWA to communication ability, socialising and participating in activities, as contributors for their life satisfaction (Cruice, Hill, et al., 2010; Cruice et al., 2006; Hilari, Wiggins, et al., 2003). Language impairment was identified as a predictor of QOL by Engell et al. (2003), Bose et al. (2009) found correlations with communication, socialisation, activities and psychosocial well-being, and Rodrigues and Leal (2013) with time post-stroke.

Overall, these data reveal an important need for coordinated efforts to help individuals with aphasia in their communication skills, as well as a need to address the many psychosocial issues which impact negatively on people's with aphasia QOL (Sarno, 1997). These studies also showed the variation of the instruments used to assess QOL of PWA, though SAQOL-39 is the most consistently used. Only Ross and Wertz (2002, 2003) used a general population-based instrument (WHOQOL-Bref), nevertheless the sample was small. Using a general population-based instrument with PWA is desirable because it allows comparisons to other long term conditions or even with general population, but bigger samples of PWA are needed. Additionally, it can be verified that

the data on Portuguese PWA is scarce; the only study available was focused on validating the SAQOL-39 and not extensive studying the influence of aphasia in PWA's QOL (Rodrigues & Leal, 2013).

2.6. Quality of life of the caregivers of people with stroke and post-stroke aphasia

The literature search strategy of this chapter was different from the previous chapters. In this chapter the opportunity was used to search with systematic review method. The search was conducted to identify studies that report data related to the QOL of the caregivers of PWA, and their QOL predictors. The following databases were searched: Medline; Pubmed; Cochrane Library; PsyclNFO; and Web of Science. Studies were considered for review if: published in peer-reviewed journals; published in English or Portuguese; reported original data; participants included adult caregivers of PWA; reported data on factors associated or predictive of PWA's caregivers QOL. No restrictions were imposed regarding study design. No other exclusion criteria were applied. Searches were conducted using the following keywords: "Aphasia" AND "caregiver" OR "relative" OR "family" (OR "families") AND "quality of life" OR "well-being" OR "life satisfaction" OR "burden" OR "consequences" OR "needs".

A total of 1745 potential citations were identified in the initial search on the 27th of March 2013. From those, 1719 were excluded because: were duplicated citations, were not peer-reviewed, were not written in English or Portuguese, did not address QOL or related subjects on PWA's caregivers, did not include adult caregivers of PWA, and did not report original data. Additionally, five (5) more studies were excluded because although they include PWA's caregivers, did not report data specifically on them. Twenty one (21) studies were included in the final analysis.

Two authors independently reviewed the titles, abstracts and keywords of every study. If the information given in the title, abstract and keywords suggested that the study might fit the inclusion criteria, the full article was retrieved for further assessment. From the full articles, the decision to exclude a study was based on agreement by both authors. Papers meeting the inclusion criteria were coded for sample data (caregivers and PWA), aims, methodology, and main findings. Two reviewers conducted the coding independently, each using a complete copy of the retrieved paper and summarised the extracted data in a data table. Agreements between the reviewers occurred for 95% of the occasions and the disagreements were solved through

discussion. The data of the 21 studies included is reported in tables. This section includes an introduction based on a broader literature review that included studies of caregivers with stroke and post-stroke aphasia and the systematic reviews' papers found; afterwards the data of the 21 studies of the systematic review are reported in the Tables 5 and 6.

The efforts to reduce the length of institutionalisation and to promote community care rely on informal caregivers (Donelan et al., 2002). Many stroke survivors return to the community with limitations and in need for support (C. Anderson, Linto, & Stewart-Wyne, 1995). In this situation, a chronically disabled person often destabilise the family life and disrupt the established balance within the family, whose members play a major role in supporting their impaired relative (Glozman, 2004; Kitzmuller et al., 2012; Kulkarni, Chamberlain, & Porrit, 1992; Rombough, Howse, Bagg, & Bartfay, 2007). Families face great challenges adjusting to the consequences of stroke and to their additional role as caregivers of a person with stroke. The pressure on caregivers can be overwhelming, occurring changes at a physical, mental, psychological and social level, in their participation, activities, and QOL (Bugge, Alexander, & Hagen, 1999; Clarke, Black, Badley, Lawrence, & Williams, 1999; Exel, Koopmanschap, & van den Berg, 2005; Rombough et al., 2007). Therefore, there is an urgent need of early recognition of caregivers' difficulties that may help to prevent or to relieve their burden as well as to develop appropriate interventions and support programs (Donelan et al., 2002; Heuvel et al., 2002). The life functioning study of people when faced with a health condition of their significant others can be named as the "third party disability" (Threats, 2010).

The studies with stroke caregivers have some inconsistences reporting the demographic variables and have lack of information on the severity of the stroke, (Exel et al., 2005; Kalra et al., 2004; Rombough et al., 2007), so comparing results is difficult. Nevertheless, some conclusions can be drawn: caregivers' QOL is worse than normative values (Bugge et al., 1999); age of the caregiver, and the patient functional status are important determinants of caregivers' QOL (Bethoux, Calmels, Gautheron, & Minaire, 1996; Jonsson et al., 2005); strain and burden are negatively associated to caregivers' QOL (Blake & Lincoln, 2000; Morimoto, Schreiner, & Asano, 2003; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998) and health status (Bugge et al., 1999; Exel et al., 2005; Tang & Chen, 2002); is positively associated with stroke severity (Bugge et al., 1999) and amount of required hours of care (Bugge et al., 1999; Jeng-Ru, Hills, Kaplan, & Johnson, 1998), but is not associated to caregivers' gender (Blake & Lincoln, 2000). Caregivers frequently report lower levels of self-esteem, depression, changes in social activities, in

marital satisfaction and financial problems (C. Anderson et al., 1995; Bethoux et al., 1996; Blake & Lincoln, 2000; Blonder, Langer, Pettigrew, & Garrity, 2007; Rombough, Howse, & Bartfay, 2006). Depression and diminished social support is associated to lower levels of life satisfaction (Grant, Elliot, Giger, & Bartolucci, 2001). Increasing responsibilities and less time to socialise and to be engaged in leisure activities diminished their QOL as well (White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). The caregiving situation seems to be negatively associated to caregivers' QOL (Bugge et al., 1999; White et al., 2004), but the literature reviewed above does not include PWA in the stroke samples, and thus it is now reviewed below.

The loss or impairment of the ability to communicate is typically devastating and frustrating to both the stroke survivor with aphasia and his or her primary caregiver and can result in fear, feeling of hopeless and depression (Hickey, 2001). As well as stroke's caregivers, family members of PWA may have a dual role in the rehabilitation process: as a partner and resource to the rehabilitation team in providing support to the PWA, and as a potential recipient of care, with their own needs and requirements for services (Michallet, Le Dorze, & Tétreault, 2001). Typically, the rehabilitation efforts rely directly on the PWA and do not address caregivers' needs, so caregivers are essentially approached as a provider of care but not as a potential recipient of care support (Threats, 2010; Worrall et al., 2010). Since the PWA may depend on the caregiver for many activities, including to communicate and to maintain and develop skills learned in therapy, understanding and supporting caregivers of PWA may help not only the caregiver, but the PWA as well (Threats, 2010). A comprehensive aphasia treatment goes beyond PWA's impairments, including interventions centred in activities and participation (Brundage et al., 2012) and ideally includes PWA and their families, caregivers, and friends, enabling people to live successfully with aphasia (K. Brown, Worrall, Davidson, & Howe, 2012; Holland, 2006).

The need to support caregivers of PWA has been recognised (Grawburg, Howe, Worrall, & Scarinci, 2012; McGurk, Kneebone, & Pit ten Cate, 2011). However, little research has focused on caregivers of stroke survivors with aphasia comparing to those without aphasia (McGurk et al., 2011). For example, in the systematic review of Rombough et al. (2006), regarding strain and burden, studies with PWA's caregivers were not found (Rombough et al., 2006). Additionally, according to McGurk et al. (2011) little information has been given in which to base recommendations (McGurk et al., 2011). Grawburg et al. (2013b) systematic review summarised the current knowledge of third party disability in aphasia and showed that there is a negative impact of aphasia in functions, activities and participation of the caregivers, although the authors mentioned that the findings are not conclusive (Grawburg et al., 2013b). Actually, many studies

studied caregivers of people with stroke, including caregivers of PWA, but did not report the caregivers of PWA data separately (Blonder et al., 2007; Bluvol & Ford-Gilboe, 2004; Choi-Kwon, Kim, Kwon, & Kim, 2005; Lawrence, Kerr, Watson, Paton, & Ellis, 2010; White, Mayo, Hanley, & Wood-Dauphinee, 2003), so it is impossible to differentiate the impact that may be due to aphasia. Despite this, some data is available about the consequences of being close to a PWA, but almost no information is available about the impact of those consequences in caregivers' QOL. The data found in the 21 studies of our systematic review is reported in the following Tables (Tables 5 and 6)

Table 5: Sample characteristics of PWA's caregivers QOL studies

Study	Caregiver data				PWA data					
	Sample size	**Relationship with PWA**	**Gender**	**Age (years)**	**Gender**	**Age (years)**	**Time post stroke**	**Aphasia severity**	**Type of aphasia**	**Physical disability**
Christensen & Anderson (1989)	11	Spouses	10 Women 1 Men	Mean: 63	1 Women 10 Men	N.a.*	6 months	N.a.*	N.a*.	Hemiparesis
Williams (1993)	40	Spouses	33 Women 7 Men	N.a.*	N.a.*	N.a.*	≥ 3 months	Mild, moderate and severe	N.a.*	N.a.*
LeDorze & Brassard (1996)	9	4 Spouses 1 Daughter 1 Mother 1 Niece 1 Cousin 1 Friend	6 Women 3 Men	Mean: 52	N.a.*	Mean: 54	≥ 2 years Mean: 7 years	mild to moderate	3 Anomic 3 Broca 2 Wernicke 1 Conduction	N.a.*
Hemsley & Code (1996)	5	4 Spouses 1 Daughter-in-law	4 Women 1 Men	N.a.*	2 Women 3 Men	Mean: 67 Range: 63-70	3 and 9 months	N.a.*	2 Anomic 1 Wernicke 1 Broca 1 Conduction	2 Hemiparesis
Denman (1998)	9	Spouses	6 Women 3 Men	N.a.*	N.a.*	N.a.*	≥ 12 months	N.a.*	N.a.*	N.a.*
Santos et al. (1999)	55	Spouses	30 Women 25 Men	Mean: 57	25 Women 30 Men	N.a.*	Range: 1-11 years	50% moderate	9 Broca/Transcortical motor 5 Wernicke/Transcortical sensorial 13 Global/Transcortical mixed 15 Anomic/Conduction 13 Aphasia sequelae	N.a.*

*Not available

Table 5: Sample characteristics of PWA's caregivers QOL studies (continued)

Study	Caregiver data				PWA data					
	Sample size	Relationship with PWA	Gender	Age (years)	Gender	Age (years)	Time post stroke	Aphasia severity	Type of aphasia	Physical disability
Pound et al. (2001)	4	Spouses	4 Women	Mean: 61 Range: 51-72	4 Men	N.a.*	Range: 12-22 months Mean: 16 months	1 Moderate 2 Severe 1 Very severe	N.a.*	2 Hemiplegia 1 Hemiparesis
Michallet et al. (2001)	6	Spouses	5 Women 1 Men	Mean: 66 Range: 59-71	N.a.*	Mean: 69 Range: 64-77	N.a.*	Severe	N.a.*	N.a.*
Michallet, Tétreault & Le Dorze (2003)	5	Spouses	4 Women 1 Man	Mean: 66 Range: 59-71	N.a.*	Mean: 69 Range: 64-77	N.a.*	Severe	3 Global 2 Mixed	N.a.*
Avent et al. (2005)	16	13 Spouses 2 Adult children 1 Parent	15 Women 1 Man	N.a.*	N.a.*	N.a.*	Range: 1-13 years Mean: 5.5 years	N.a.*	N.a.*	N.a.*
Bakas et al. (2006)	46	20 Spouses 19 Adult Children 7 Other	42 Women 4 Men	Mean: 52 Range: 21-76	20 Women 26 Men	Mean: 64 Range: 38-85	N.a.*	N.a.*	N.a.*	N.a.*
Franzén-Dahlin et al. (2008)	77	Significant others	N.a.*	N.a.*	32 Women 45 Men	Mean: 74	6 months	1 to 4 (ANELT)	N.a.*	N.a.*
Le Dorze et al. (2009)	1	Daughter	Women	N.a.*	1 Man	60	N.a.*	Severe	Mixed aphasia	Hemiparesis
Natterlund (2010)	14	7 Spouses 4 Parents 1 Sibling 1 Child 1 Close friend	7 Women 7 Men	N.a.*	5 Women 9 Men	Mean: 56 Range: 28-70	N.a.*	N.a.*	Expressive	N.a.*

*Not available

Table 5: Sample characteristics of PWA's caregivers QOL studies (continued)

Study	Caregiver data				PWA data					
	Sample size	Relationship with PWA	Gender	Age (years)	Gender	Age (years)	Time post stroke	Aphasia severity	Type of aphasia	Physical disability
Le Dorze & Signori (2010)	11	Spouses	9 Women 2 Men	Mean: 61 Range: 51-68	N.a*.	Mean: 64 Range: 51-76	≥ 3 years Mean: 7 years	Mild to severe	N.a.*	Residual to moderate
Nystrom (2011)	17	10 Spouses 6 Adult children 1 Parent	11 Women 6 Men	Range: 35-79	6 Women 11 Men	Range: 25-88	N.a.*	N.a.*	N.a.*	N.a.*
McGurk et al. (2011)	150	127 Spouses 16 Adult children	121 Women 29 Men		47 Women 103 Men	N.a.*	N.a.*	N.a.*	N.a.*	N.a.*
Manders et al. (2011)	77	54 Spouses 23 Adult children	N.a.*	Partners' mean: 60 Children's mean: 41	N.a.*	N.a.*	30% ≤ 6 months 41% > 6 & ≤ 2 years 29% > 2 years	N.a.*	N.a.*	N.a.*
Brown et al. (2011)	24	19 Spouses 3 Parents 1 Brother 1 Adult children	15 Women 9 Men	Mean: 62 Range: 40-87	11 Women 12 Men	Mean: 63 Range: 38-86	≥ 2 years	17 Mild 6 Moderate to severe	N.a.*	N.a.*
Kitzmuller et al. (2012)	11	Spouses Adult children	N.a.*	N.a.*	N.a.*	N.a.*	≥ 3 years	N.a.*	N.a.*	N.a.*
Howe et al. (2012)	48	28 Spouses 5 Siblings 7 Adult children 2 Parents 6 Other relatives	36 Women 12 Men	Mean: 61 Range: 24-83	17 Women 31 Men	Mean: 64 Range:32-83	N.a.*	N.a.*	N.a.*	N.a.*

*Not available

In these studies, the sample size was between one and 150 caregivers, the great majority with less than 50 individuals. They were mainly spouses and women, and had an overall minimum age of 21 years and a maximum of 87 years. Regarding PWA, a large amount of data is unavailable but we can still conclude that the majority were men and that, generally, the minimum age was 25 years and the maximum 88 years. The majority of the studies did not refer to severity or type of aphasia and to the physical disability of the PWA. Many studies did not refer any data on time post onset, but on those available, the minimum time was less than six months (E. Manders, Marien, & Janssen, 2011) and the maximum 13 years (Avent et al., 2005). Almost all the studies used qualitative methodology (see Table 6).

Based on the aims and findings of the studies, it can be concluded that the studies mainly describe the experience, identify the consequences and needs of those closely related or caring for PWA. One study approached caregivers' life situation predictors (Franzén-Dahlin et al., 2008) and three aphasia characteristics as predictors of caregivers' experience (Hemsley & Code, 1996; McGurk et al., 2011; S. Williams, 1993). According to Brown's et al. (2012) study, being a caregiver of a PWA impacts significantly the life situation (K. Brown et al., 2012), but no study reported on caregivers' QOL or its predictors (see Table 6).

Table 6: Studies aims, methodology and main findings

Study	Aims	Methodology	Main findings
Christensen & Anderson (1989)	Examine the impact of aphasia on spouse role change, emotional problems, social adjustment, and partner's perceived communication abilities	Quantitative	77% Spouses of PWA experienced role changes. Spouses of PWA have significant more role changes than spouses of people with stroke non-aphasic Spouses of PWA had more social problems than spouses of people with stroke non-aphasic 36% Spouses of PWA report emotional and/or health problems Spouses of PWA tend to talk more with others about their partner's problems
Williams (1993)	Examine changes in marital satisfaction	Quantitative	Significant differences between spouses' pre stroke and post stroke marital satisfaction Areas most referred as affected: lifestyle, finances, sex, interpersonal communications Marital satisfaction is not associated to severity of aphasia, time post stroke, or length of marriage Marital satisfaction is associated to the knowledge about aphasia: the more the knowledge, the less the negative impact on marital satisfaction
LeDorze & Brassard (1996)	Describe the experience of aphasia on the basis of personal accounts	Qualitative	Interpersonal relationships: role changes; change in intimate relationships; changes in household habits; loss of friends Changes is communicative situations, perception of loss of interest in communication on the part of the PWA Irritation, stress, annoyance, discouragement, effort, fatigue, more responsibilities, more concernments, health problems Feelings of stigmatization when others address the relative or friend instead of PWA Restricted activities: dropping a course; giving up; abandoning plans for vacation; disinvestment in one's career Coping behaviours used by relatives or friends: making new friends amongst people who are also familiar with aphasia; distancing oneself from the PWA; joining association
Hemsley & Code (1996)	Identify associations between clinical and functional aphasia and perceptions of emotional and psychosocial adjustment Determine subjective well-being and optimism of significant others of PWA	Quantitative	Poor emotional or psychosocial adjustment; Social dysfunction and anxiety were areas of poor adjustment Social dysfunction may be a product of the presence of aphasia regardless of its type or severity
Denman (1998)	Identify the needs	Qualitative	Needs: support, information, role change, training and day/respite care
Santos, et al. (1999)	Analyse the opinions of spouses of PWA about problems affecting their QOL	Quantitative	Important modifications in their own lives (life changed, had consequent problems and their mood altered). No significant differences found between husbands and wives of PWA.
Pound et al. (2001)	Examine the impact of aphasia on the spouses' lives	Qualitative	Changes: gave up job; no freedom; living on nerves; strain; anxiety about further strokes; less social activities; less contact with children, family and friends; burden; frustration with communication Need for respite
Michallet et al. (2001)	Identify and describe the needs perceived by spouses of PWA	Qualitative	Needs: information; enhance communication with the PWA; have better interpersonal relations with family and social network; be considered as a partner in the caring process; emotional and practical support; respite Sense of isolation and exclusion
Michallet, Tétreault & Le Dorze (2003)	Identify the consequences of severe aphasia as experienced by spouses of PWA	Qualitative	Changes in lifestyle habits: interpersonal relationships, responsibilities, leisure activities, and finances Spouses experienced: fatigue, anxiety, discouragement, loss of privacy, social isolation and burden Coping strategies based on the problems or on the control of the significance of them
Franzén-Dahlin et al. (2008)	Examine predictors of life situation of the significant other of aphasic stroke patients	Quantitative	Living with a PWA affected significantly the life situation of significant others Need for assistance is a life situation predictor: the higher the need, more affected is the life situation Perceived personality change is a life situation significant predictor: the more the change perceived in the PWA, the more affected the life situation

Table 6: Studies aims, methodology and main findings (continued)

Study	Aims	Methodology	Main findings
Bakas et al. (2006)	Compares selected outcomes among caregivers of aphasic and non-aphasic stroke survivors	Quantitative	Caregivers of PWA experienced more difficulty with tasks than caregivers of non-aphasic Most difficult tasks for caregivers of PWA: communicating with PWA; managing sadness, depression; dealing with finances; and talking with health professionals. Caregivers of PWA reported lack of time for social activities with family and friends Negative changes for caregivers of PWA in level of energy, financial well-being, emotional well-being and roles in life
Avent et al. (2005)	Identify information needed for family members at the onset of, initial rehabilitation, and chronic phases of aphasia	Qualitative	Information needed in all phases: about aphasia; psychosocial support and hopefulness At the onset: significant need for generic information about aphasia and its causes; realistic and positive prognostic information; co-existing behaviour and medical changes resulting from stroke; resources to help family cope with aphasia During treatment: information about the process of aphasia treatment; instructions about how to maximize communicative effectiveness during interactions; about co-existing behaviours and medical conditions (e.g. depression); and about resources (someone to talk to with experience of aphasia) Chronic phase: need for community based information such as volunteer opportunities
Le Dorze et al. (2009)	Describe the experience of a daughter's adaptation process to her father's stroke and aphasia during the first year post-stroke	Qualitative	Sources of stress change over time: negative consequences diminished and more positive indicators emerged Changes: relationship; communication; concernments (relative's survival, health and communication); reduction of leisure and social activities Needs: social and family support and to remain hopeful Conversational strategies provided by speech and language therapists attenuated changes in relationships; accessing information was important to help the PWA, to keep hopeful and contributed to the sense of doing something useful
Natterlund (2010)	Describe the influence of aphasia on caregivers' life situation	Qualitative	Great changes in life Loss of friends Communication problems in the beginning Sense of emotional loneliness Sense of being the one who does the majority of the practical chores Need for support
Le Dorze & Signori (2010)	Identify needs, barriers and facilitators	Qualitative	Practical and emotional support needs Concern about PWA's health, communication, independence and well-being More responsibilities and sense of obligation Facilitators: availability of close others to provide help Barriers: organizational
Nystrom (2011)	Identify the consequences of being closely related to a PWA	Qualitative	Life is characterized by: loss of freedom; staying; new form of relationship; growing strong together with others Being a bridge between the PWA and the surrounding world

Table 6: Studies aims, methodology and main findings (continued)

Study	Aims	Methodology	Main findings
McGurk et al. (2011)	To assess coping strategies used by informal caregivers of PWA to manage with communication problems. To study the association between depressive symptoms and coping strategies	Quantitative	46% of the participants revealed high levels of depressive symptoms (DS) More severe communication impairment of the PWA was associated with greater DS of the caregiver PWA's communication impairment does not predict caregivers' DS after controlling the effect of coping Participants satisfied with informal and emotional support reported less DS Satisfaction with practical support was not associated to DS No significant associations were found between DS and: age; gender; PWA's dependency level; or time post stroke Anticipated social support is significantly related to caregivers' DS Coping strategies most used: acceptance; active coping; planning; positive reframing; self-distraction; attentiveness to stroke survivors; and proactive facilitating communication Coping strategies least used were avoidant-type (e.g. denial, substance use) Active coping and positive reframing were associated to lower levels of DS Self-distraction, denial, substance use, behavioural disengagement, avoidance and self-blame were associated with higher levels of DS. Problem-focused approach strategies (e.g. active coping, planning) and emotion-focused approach strategies (e.g. positive reframing, acceptance) were most often used to cope with communication problems.
Manders et al. (2011)	Investigate how important significant others find it to be informed, supported and trained by SLP Investigate to what extent they perceive their expectations and needs to these aspects to be fulfilled	Qualitative	98% stressed the importance of practical training in learning how to communicate with PWA 90% stressed the importance of full participation in rehabilitation process Need for information (oral and written), and training
Brown et al. (2011)	Explore family members of PWA's perspective on the meaning of living successfully with aphasia	Qualitative	Aphasia affects the whole family and changes caregivers' activities and participation Getting involved with life, support for the PWA, family members' own needs, putting life into perspective, focusing on and celebrating strengths and improvements, sense of hope and positivity, and the experiences with services are important to live successfully with aphasia Closely related with the experience of satisfying relationships and interactions. Needs: information; support; have time for themselves; respite; put their priorities first; balance expectations
Kitzmuller et al. (2012)	Illuminate the long-term experience of family life after stroke	Qualitative	Gap between children and their disabled parent More misunderstandings and conflicts within the couple Less social activities and social network; loss of friends; loneliness Emotional problems Role changes More responsibilities, burden
Howe et al. (2012)	Identify rehabilitation goals family members of PWA have for themselves	Qualitative	Living with a person with aphasia impacts on their emotional, mental and physical well-being Goals/needs: inclusion in rehabilitation; provision of hope and positivity; ability to communicate and maintain their relationship with the PWA; supply support and information; opportunity to look after their own well-being (e.g. have time for themselves; respite); ability to cope with new responsibilities

From all these studies, it can be observed that caregivers reported mainly emotional and social changes. Thirteen (13) of these studies reported greater emotional changes on PWA's

caregivers (Bakas, Kroenke, Plue, Perkins, & Williams, 2006; Christensen & Anderson, 1989; Hemsley & Code, 1996; Kitzmuller et al., 2012; Le Dorze, Brassard, Larfeuil, & Allaire, 1996; Le Dorze & Signori, 2010; Le Dorze, Tremblay, & Croteau, 2009; E. Manders et al., 2011; McGurk et al., 2011; Michallet et al., 2001; Nätterlund, 2010; Pound, Parr, & Duchan, 2001; Santos, Farrajota, Caldas, & Sousa, 1999). Emotional problems were mentioned (Bakas et al., 2006; Christensen & Anderson, 1989; Hemsley & Code, 1996; Kitzmuller et al., 2012; Santos et al., 1999) as well as depression (Bakas et al., 2006; A. Manders et al., 2010; McGurk et al., 2011) and concerns about PWA's health and communication (Le Dorze et al., 1996; Le Dorze & Signori, 2010; Le Dorze et al., 2009; Pound et al., 2001). Depression seems to be associated with communication impairment, with satisfaction with informal and emotional support, with anticipated social support, and with active coping and positive reframing (McGurk et al., 2011) of the caregivers. The concerns are especially about the PWA and his/her health. PWA's caregivers were more concerned about their relative's everyday well-being than their own needs and life (Le Dorze et al., 1996; Le Dorze & Signori, 2010; Le Dorze et al., 2009; Pound et al., 2001). Other feelings such as anxiety, irritation, strain, stress (Hemsley & Code, 1996; Le Dorze et al., 1996; Michallet et al., 2001; Pound et al., 2001), annoyance, sadness (Bakas et al., 2006; Le Dorze et al., 1996), sense of emotional loneliness (Nätterlund, 2010), and discouragement (Le Dorze et al., 1996; Michallet et al., 2003), were also reported.

Great changes occurred in the social level of PWA caregivers' lives as well (Bakas et al., 2006; K. Brown et al., 2011; Christensen & Anderson, 1989; Hemsley & Code, 1996; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze et al., 2009; Michallet et al., 2001; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011; Pound et al., 2001; S. Williams, 1993). Nine (9) studies reported changes in relationships, which were manifested in their marital relations, their relationships with family, with friends and with others from their social circle. For some caregivers, the loss of friends was described as the hardest part (Christensen & Anderson, 1989; Hemsley & Code, 1996; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze et al., 2009; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011; Pound et al., 2001). Seven studies reported communication problems (Bakas et al., 2006; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze et al., 2009; Nätterlund, 2010; Pound et al., 2001; S. Williams, 1993) that were perceived as devastating, as a source of stress, and leading to loneliness (Nätterlund, 2010).

Six studies reported activities changes (Bakas et al., 2006; K. Brown et al., 2011; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze et al., 2009; Michallet et al., 2003; Pound et al., 2001), and two participation changes (K. Brown et al., 2011; Le Dorze et al., 1996). Loss of freedom and

loss of privacy were also felt by caregivers, especially those who live with the PWA (they had to take part as informal caregivers whether they agreed or not) (Michallet et al., 2003; Nystrom, 2011; Pound et al., 2001). Loneliness, social isolation (Kitzmuller et al., 2012; Michallet et al., 2001; Michallet et al., 2003), exclusion (Le Dorze et al., 1996; Michallet et al., 2001) and stigmatisation (Le Dorze et al., 1996) were also reported. Social isolation was reported not only as a "natural" consequence (others stay apart), but also, in a certain degree, as voluntary by the PWA and their caregivers due to the communication difficulties (Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011).

Regarding other changes, responsibilities were the most referred to in the studies (Howe et al., 2012; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze & Signori, 2010; Michallet et al., 2003; Natterlund, 2010), followed by burden (Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze & Signori, 2010; Michallet et al., 2003; Pound et al., 2001) and role changes (Bakas et al., 2006; Christensen & Anderson, 1989; Kitzmuller et al., 2012; Le Dorze et al., 1996). Caregivers perceived that all responsibilities lay on them, which could be a source of pressure, stress, irritation, fatigue, exhaustion and burden (Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011). Role changes happened, wherein the caregivers took over roles that the PWA no longer assumed, and this can also be a source of stress (Denman, 1998; Michallet et al., 2003; Nätterlund, 2010). Financial changes (Bakas et al., 2006; Michallet et al., 2003; S. Williams, 1993), health problems (Christensen & Anderson, 1989; Le Dorze et al., 1996) and relinquishing plans (Le Dorze et al., 1996; Pound et al., 2001) were also mentioned. Financial problems were, as well, a source of stress (Michallet et al., 2003) and due to the lack of time to take over all the responsibilities, some carers had to take an early retirement to care for their spouses (Michallet et al., 2003; Nystrom, 2011).

Concerning needs, the most frequently reported needs in the studies analysed were support (e.g. support in taking care of a PWA; emotional support for dealing with the consequences of aphasia and day to-day tasks; support for redefining their roles and their life projects) (K. Brown et al., 2011; Denman, 1998; Franzén-Dahlin et al., 2008; Howe et al., 2012; Le Dorze & Signori, 2010; Le Dorze et al., 2009; Michallet et al., 2001; Nätterlund, 2010), information (Avent et al., 2005; K. Brown et al., 2011; Denman, 1998; Howe et al., 2012; E. Manders et al., 2011; Michallet et al., 2001; Nätterlund, 2010), training (e.g. communication training) (Denman, 1998; Howe et al., 2012; Le Dorze et al., 2009; E. Manders et al., 2011; Michallet et al., 2001) and respite (K. Brown et al., 2011; Denman, 1998; Howe et al., 2012; Michallet et al., 2001; Pound et al., 2001). Some other studies mentioned the need to enhance communication with PWA (Howe et al., 2012;

E. Manders et al., 2011; Michallet et al., 2001), to have time for themselves (Bakas et al., 2006; K. Brown et al., 2011; Howe et al., 2012) and to be provided with hope and positivity (Howe et al., 2012; Le Dorze et al., 2009). Positive reframing, support and attentiveness to the PWA, and availability of others to provide help are coping strategies important for caregivers (K. Brown et al., 2011; Hemsley & Code, 1996; Le Dorze & Signori, 2010; McGurk et al., 2011; Michallet et al., 2003).

Marital satisfaction is affected by the presence of aphasia (S. Williams, 1993). Spouses reported decreased sexual desire and some considered divorce, although in many cases it did not happen. A new form of relationship and coping was developed (Nätterlund, 2010; Nystrom, 2011). Time post stroke and severity of aphasia are not associated to marital satisfaction, but the knowledge about aphasia is (S. Williams, 1993).

A systematic review of studies reporting the consequences of chronic diseases (other than stroke) on caregivers' lives identified some variables or predictors of caregivers' QOL, namely: severity of the impairment; functional disability; cognitive and behavioural disorders; and impaired social interactions of the disabled person; age; gender; educational level and socioeconomic status of both; coping strategies; social support; perception of support availability; and type of relationship of the caregiver (Glozman, 2004). The great majority of the analysed studies that included PWA's caregivers did not report these data in detail or did not mention it at all, and this is outlined below.

Functional disability of the PWA, cognitive and behavioural disorders of the PWA and socioeconomic level of PWA and caregiver are not reported in the 21 studies analysed. Educational level was reported in two studies, but only for the caregivers (Bakas et al., 2006; McGurk et al., 2011). Impairment severity, physical disability, gender, and age of the PWA and/or of the caregiver are reported in some of them (Avent et al., 2005; Bakas et al., 2006; K. Brown et al., 2011; Christensen & Anderson, 1989; Denman, 1998; Franzén-Dahlin et al., 2008; Hemsley & Code, 1996; Howe et al., 2012; Le Dorze et al., 1996; Le Dorze & Signori, 2010; Le Dorze et al., 2009; McGurk et al., 2011; Michallet et al., 2001; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011; Pound et al., 2001; Santos et al., 1999; S. Williams, 1993). The type of relationship of the caregiver with the PWA is reported in all studies. However, except for Santos et al. (1999) study's that presented no differences according to gender in the modifications occurred in caregivers' lives (Santos et al., 1999), all these variables were only mentioned to characterise the samples, to check correlations with depressive symptoms or marital satisfaction, and not to determine whether these variables may influence caregivers' QOL or not (Avent et al., 2005;

Bakas et al., 2006; K. Brown et al., 2011; Christensen & Anderson, 1989; Denman, 1998; Franzén-Dahlin et al., 2008; Hemsley & Code, 1996; Howe et al., 2012; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze & Signori, 2010; Le Dorze et al., 2009; E. Manders et al., 2011; McGurk et al., 2011; Michallet et al., 2001; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011; Pound et al., 2001; S. Williams, 1993). Therefore, comparisons cannot be made between these studies, and even between them and studies with a more general chronic sample. It will be essential in future research with caregivers of PWA to systematically collect and report these data when publishing in order to provide better comparisons among studies, relate variables, and provide a better understanding of disability impact on caregivers.

Some consequences of living and caring for a PWA were identified, although their QOL has not been explored. According to Exel et al. (2005), patients and caregivers' QOL is a strong indicator in identifying caregivers at risk. Studying these outcomes could help to relieve their burden and prevent from further institutionalization of the person with stroke or of the caregiver (Exel et al., 2005). In fact, it appears that aphasia has the potential to reduce QOL, but we don't know if all these changes significantly impact in their QOL or even if some variables are stronger predictors of caregivers' QOL than others. The reviewed studies highlighted important issues resulting from communication impairment in caregivers, but there might be several issues to consider additionally, and further research is needed. From all the consequences of stroke, aphasia is a very specific one, thus it might be studied in order to better understand the needs and priorities of PWA and their caregivers. As a result, healthcare could be better focused on PWA's caregivers' needs and provide appropriate, relevant and cost-effective interventions and referrals for them. As caregivers are an important source of support and a driving force for PWA's participation in society, caregiver-focused programs may reduce the burden of the impairment even for society. According to White et al. (2004), maintaining caregivers' QOL is a very significant factor in the ability and willingness to provide the care required to keep a family member with stroke in the community (White et al., 2004). This suggests an important role for professionals in providing support to caregivers so that they can continue in this role if they wish (Wilkinson et al., 1997). Identifying caregiver QOL is then crucial.

It is also important in speech and language therapy, to understand the impact of aphasia on the caregivers' QOL and on their needs, and use it to determine the aims of the intervention. Caregivers' views of living with aphasia and QOL may contribute with valuable insights into important processes that may influence clinical interventions and community-based services for PWA and their caregivers (K. Brown et al., 2011), and caregivers described their interest and need

to be involved in rehabilitation (Howe et al., 2012). As speech and language therapists are knowledgeable about communication and aphasia, they are essential health professionals in planning and implementing services that will promote social participation and QOL of all those affected by aphasia (Le Dorze & Signori, 2010).

CHAPTER 3: Aims and Method

As shown in the literature review, the data about Portuguese general population QOL is scarce and even scarcer is the data about the QOL of Portuguese PWA and their caregivers. Since the QOL of Portuguese general population was not extensively documented, this study includes the study of a sample of Portuguese general population. Until now, the Portuguese studies have been more focused in translating and adapting instruments, so little attention has been given to the study of variables' influence in QOL for general population and PWA, and no published data was found on caregivers of PWA QOL. This study intended to fill this gap studying the influence of a huge range of variables, such as sociodemographic, language and communication, and speech and language therapy (SLT) related, in QOL using a population-based instrument to make it possible to compare with various groups. As SR is a key aspect for the PWA and their caregivers, the influence of the mentioned variables in SR are also studied.

3.1. Aims of the study

This project aims to study the influence of communication disability in PWA's and their caregivers' QOL and SR. We divided this project in three studies: (1) the study of the QOL and SR of Portuguese general population; (2) the study of the QOL and SR of PWA; (3) the study of the QOL and SR of PWA's caregivers. The aims of the overall study are:

- To characterise the QOL and the SR of Portuguese general population, PWA and caregivers;
- To determine the influence of sociodemographic variables in the QOL and SR of Portuguese general population;
- To determine the influence of sociodemographic variables and variables related to aphasia in the QOL and SR of PWA and caregivers;
- To compare the QOL of Portuguese general population, PWA and caregivers;
- To compare SR satisfaction of Portuguese general population, PWA and caregivers
- To evaluate PWA's experience of completing the WHOQOL-Bref from speech and language therapists' perspectives of ease of understanding and responding, assistance required, and length of administration.

3.2. Method

3.2.1. Study 1 (Portuguese general population sample)

3.2.1.1. Study design and sample characteristics

This is a cross-sectional correlational study. The sample was composed of 255 individuals recruited by a snowball sampling technique that met the following inclusion criteria: to be Portuguese; to live in Portugal; to have 25 years of age or more. More sample procedures details will be given in section 3.1.3.

The sample sizes influence statistical tests results, so the power of a given test should be analysed to define the minimal sample size required to detect significant differences when differences really exists. Similarly, the minimum effect size that is likely to be detected can be calculated using a given sample (Field, 2009). The sample sizes required for high power values of the tests used in this study (correlation, qui-square and regression) and for minimal effect sizes were calculated with the G*Power 3.5.1. tool (see Table 7).

Table 7: Sample size for minimum effect sizes and high test power

Test	Power	Alpha	Effect size	Sample
Correlation	0.95	0.05	0.10	1077
Qui-square	0.95	0.05	0.10	2359
Regression	0.95	0.05	0.02	934

Calculation was also undertaken for the same standard of power, but using the sample size collected (N=255). The effect sizes detected with this sample are small for correlation and regression, and medium for Chi-square (see Table 4). Although a larger sample is required for minimum effect sizes (see Table 7), 255 participants is still adequate (see Table 8).

Table 8: Effect size for a sample of 255 and high test power

Test	Sample	Power	Alpha	Effect size
Correlation	255	0.95	0.05	0.20
Chi-square	255	0.95	0.05	0.30
Regression	255	0.95	0.05	0.07

There is no data available in Portugal to determine the representativeness of a sample with the sociodemographic characteristics of this study sample, however it is a close match to Portuguese general population regarding gender (47.78% males and 52.22% females) and mean

age (mean age is 41.8 years), according to the National Institute of Statistics (INE, 2012). The percentage of the participants from the Portuguese islands is over-represented in the sample when compared to Portuguese general population proportions (INE, 2012): 95.13% of Portuguese population live in mainland and 4.87% in the islands (INE, 2012).

3.2.1.2. Measures

All 255 participants completed the European Portuguese version of the World Health Organization Quality of Life short-form instrument (WHOQOL-Bref) (Serra et al., 2006), the SR domain of the WHOQOL-100 (Canavarro et al., 2009), the European Portuguese version of the Center for Epidemiological Studies Depression Scale (CES-D), (Gonçalves & Fagulha, 2004) and a demographic data sheet.

3.2.1.2.1. The World Health Organization Quality of Life Scale – Bref, Portuguese version

The WHOQOL-Bref has good to excellent psychometric properties (Chen et al., 2009; Fleck et al., 2000; Huang et al., 2006; Kalfoss et al., 2008; Liang et al., 2009; Noerholm et al., 2004; Serra et al., 2006; Skevington et al., 2004; Usefy et al., 2010; Wang et al., 2006; Yao & Wu, 2009; Yao et al., 2008). It is a self-administered instrument, although interviewer-assisted administration is allowed when necessary (WHO, 1997). It is available in more than 40 languages is cross-culturally comparable (Skevington et al., 2004) enabling comparisons of diverse populations in various cultural settings and countries, and thus has cultural relevance, is comprehensive, is sensitive to the various domains of QOL, and uses a subjective assessment approach (CPRO, 2007; WHO, 1997). The guidelines used in the development of the WHOQOL instruments allow comparisons between cultures and also between different services or treatments and longitudinal studies of interventions with less risk of bias (Power et al., 2005; WHOQOLGroup, 1993). Moreover, the WHOQOL-Bref includes the environment and the interactions between the people and the environment, features which have not been specifically emphasised in the development of many other QOL assessments (Cruice, Hirsch, et al., 2000; WHO, 1997).

This instrument (see Appendix A) has 24 facets (areas) and is composed of 26 items distributed in a four-factor structure: physical domain (seven items); psychological domain (six

items); SR (three items); and environment (eight items). The WHOQOL-Bref contains one item from each of the 24 facets of WHOQOL-100 (the instrument that led to WHOQO-Bref) and two additional items intended as indicators of overall QOL (Canavarro et al., 2009; Serra et al., 2006; WHO, 1997). The facets of the SR domain are: personal relationships; practical social support; and sexual activity. Likewise other versions, all the domains of the Portuguese instrument have good internal consistency (0.87-0.78) except the SR domain in which is acceptable (0.64) (Hawthorne, Herrman, et al., 2006; Serra et al., 2006; Skevington et al., 2004). The SR domain has the least number of items (three) which contributes to the weakness of this domain (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000). Given that SR is a core aspect in this study, the same domain of the WHOQOL-100 (12 items and better internal consistency) is also used in this research (further information about this domain below). All the questions of the WHOQOL-Bref are rated in a five-point Likert scale and the scores are transformed into a zero to 100 scale. Twenty-four (24) of the items are rated, scores for the four domains are calculated, and overall QOL results from the scores of the remaining two questions. All the domains are scored separately. It includes questions such as: “How would you rate your quality of life?”; “To what extent do you feel your life to be meaningful?”; “How satisfied are you with your personal relationships?”. The score of each question is from one to five. The higher the score, the better the QOL or the satisfaction with life domains (WHO, 1997). Furthermore, demographic data is also collected by this instrument: age, gender, educational level, marital status, profession, living place and health status (Serra et al., 2006).

3.2.1.2.2. The World Health Organization Quality of Life Scale - 100 social relationships domain, Portuguese version

The WHOQOL-100 is the long version of the WHOQOL-Bref with 100 items (Canavarro et al., 2009). It is a self-administered instrument, and similarly to WHOQOL-Bref, interviewer-assisted administration is allowed when necessary (WHO, 1997). All the domains of this instrument have good internal consistency (0.94-0.84), including the SR domain (0.85), which was the only WHOQOL-100 domain used in this study (see Appendix B). We intended to study the impact of aphasia in SR, and for this purpose we chose to use, additionally, a complete version of this domain (composed of 12 items) with the results compared with those of WHOQOL-Bref SR domain. The questions include the facets of personal relationships (four items), practical social support (four items), and sexual activity (four items) which are rated in a five-point Likert scale.

The score of each question is from one to five. The higher the score, the better the satisfaction with SR (WHO, 1997).

3.2.1.2.3. The Center for Epidemiologic Studies Depression Scale, Portuguese version

The CES-D is a self-report depression scale originally designed to measure the frequency of depressive symptoms in general population (Radloff, 1977). It is widely used (Kim et al., 1999; Larsen et al., 2013; Simpson & Carter, 2013) and its psychometric properties are good (Gonçalves & Fagulha, 2004; Radloff, 1977; Simpson & Carter, 2013). It asks about the frequency of symptoms felt in the last week through questions like: "I felt that I could not shake off the blues even with help from my family or friends"; "I felt that everything I did was an effort"; "I felt lonely" (see Appendix C). It is composed of 20 items that are scored in a four-point Likert scale between zero and three. The total score may range from zero to 60 and the cut-off point for important depressive symptoms detected is 20. The higher the score, the greater the frequency of depressive symptoms (Gonçalves & Fagulha, 2004; Radloff, 1977). In this study, the version used was the 20 items Portuguese version (Gonçalves & Fagulha, 2004).

3.2.1.2.4. Sociodemographic datasheet

A questionnaire was used to collect additional sociodemographic data regarding occupation, cohabitation and socioeconomic status (see Appendix D).

3.2.1.3. Ethical and sampling procedures

Ethical approval was given by an independent Ethics Committee (see Appendix E).

The snowball sample technique used in this study consisted of a first round composed of 37 people (primary seeds) from all the 11 Portuguese regions (Minho, Trás-os-Montes, Douro Litoral, Beira Alta, Beira Baixa, Beira Litoral, Ribatejo, Estremadura, Alto Alentejo, Baixo Altentejo, and Algarve) and the two islands (Açores and Madeira). Three primary seeds were identified per region and were asked to participate in the study. Some were not living at that moment in the region or were not able to participate. Questionnaires were distributed in envelopes personally or by post to author's own acquaintances who agreed to participate and they were asked to

distribute the questionnaires to other people they knew who met the inclusion criteria. The questionnaires were returned personally or by post in sealed envelopes.

All the questionnaires were given inside an open envelope with a data sheet explaining the aims of the study, the procedures required answering questionnaires (e.g. if the person is illiterate, the questionnaires should be read aloud other person), and contacting the author (see Appendix F). Once completed, the questionnaires were given by the participants to the primary seeds in sealed envelopes and were returned personally or by post to the author. The author coded every questionnaire and inserted the data in an electronic database.

Five hundred and forty (540) questionnaires were distributed and 313 were returned (58% response rate). Fifty eight (58) questionnaires were not used due to missing data and according to WHO (1996) criteria (when more than 20% of the data is missing from an assessment or when the domains could not be calculated because of missing data). The missing data had no identifiable patterns.

3.2.1.4. Statistical Analysis

Data was analysed using SPSS 16.0 for Windows. As the WHOQOL-Bref scale is ordinal and the results of overall QOL are based on the responses of two questions (both in a five-point Likert scale), non-parametric tests were used. Descriptive statistics was used to characterize the QOL and SR of Portuguese general population, as well as Spearman's rho coefficient that was used to measure the correlation between QOL and SR and: QOL domains; age; level of education; number of cohabitants; socioeconomic status; emotional status. The Chi-square test was used to evaluate the association between QOL and SR and gender and the Kruskal-Wallis test was used to identify possible differences among QOL and SR according to: living place; marital status; type of cohabitants; occupation; and health status. A regression analysis (stepwise method) was undertaken to identify which variables better explained overall QOL and SR. Regression analysis (stepwise method) was also used to identify the life domains and the SR WHOQOL scales items that better explained overall QOL.

3.2.2. Study 2 and study 3 (PWA and caregivers' samples)

3.2.2.1. Study design and sample characteristics

The studies 2 and 3 are cross-sectional descriptive, correlational and comparative studies.

The sample of this study was composed of 25 PWA and 25 caregivers. PWA met the following inclusion criteria: to be 20 years of age or more; to be Portuguese; living in Portugal; to have pre-morbid European Portuguese language proficiency; to have aphasia following stroke for at least three months; to have good auditory comprehension (outcomes of seven or more in the simple auditory comprehension test of the Lisbon Aphasia Assessment Battery (LAAB)); no known history of cognitive and auditory disabilities that could interfere with the individual's performance in the investigation. The inclusion criteria for the caregivers were to: live in Portugal; be Portuguese; be a native European Portuguese speaker; be with the PWA for at least an average of eight hours per day; and have no history of cognitive disabilities or other that could interfere with language or communication.

PWA were recruited from five public hospitals (Centro Hospitalar do Porto – Hospital Geral de Santo António; Unidade Local de Saúde de Matosinhos E.P.E. – Hospital Pedro Hispano; Hospital Espírito Santo de Évora, E.P.E.; Hospital de Faro, E.P.E.; Centro Hospitalar de Trás-os-Montes e Alto Douro, E.P.E. – Unidade Hospitalar de Chaves), one rehabilitation centre (Centro de Medicina de Reabilitação do Sul), and through independent speech and language therapists working with PWA at their dwelling-place.

The sample sizes required for high values of tests power and minimal effect sizes were not calculated for study 2 and 3 since the samples sizes are small and the power of the tests are obviously limited by this. We do not want to make inferences to population.

3.2.2.2. Measures

All the PWA completed the European Portuguese version of the following instruments: WHOQOL-Bref (Serra et al., 2006); the SR domain of the WHOQOL-100 (Canavarro et al., 2009); the CES-D, (Gonçalves & Fagulha, 2004); the Frenchay Activities Index (FAI) (Jesus, Marques, Roberto, Rosa, & Patrício, In Press-b; Wade, Legh-Smith, & Hewer, 1985); the BI (Jesus, Marques, Roberto, Rosa, & Patrício, In Press-a; Mahoney & Barthel, 1965); the Mini-Mental State Modificado (MMSM) (Matos & Jesus, 2011b); the Communication Disability Profile (CDP) (Matos & Jesus, 2011a); the LAAB (Castro-Caldas, 1979; Damásio, 1973; Ferro, 1986); and a demographic

data sheet. For this sample, the interviewer assessing the PWA was additionally asked to rate the PWA's completion of the WHOQOL-Bref on a visual analogue scale.

The caregivers completed the European Portuguese versions of the: WHOQOL-Bref (Serra et al., 2006); the SR domain of the WHOQOL-100 (Canavarro et al., 2009); the CES-D (Gonçalves & Fagulha, 2004); and the Carer's Assessment of Managing Index (CAMI) (Brito, 2002).

The WHOQOL-Bref, the SR domain of the WHOQOL-100 and the CES-D was described in section 3.2.1.2.

3.2.2.2.1. Frenchay Activities Index, Portuguese version[1]

The FAI is composed by 15 items that assesses the frequency of activities performed in the last three and six months in people with stroke (see Appendix G). The activities require some decision-making and organisation within and outside home such as "In the last three months how often have you undertaken preparing meals?" or "In the last six months how often have you undertaken travel outing/car ride?". The answers are given in a four-point Likert scale from zero to three (e.g. 0=Never; 1=less than once per week; 2=1-2 times per week; 3=most days). Frequency changes according to the activity and the period of time they are referring to (three or six months). The range is zero to 45. Higher scores reveal higher levels of frequency of activities performed (Wade et al., 1985). There is no Portuguese version of the FAI. Martins, Ribeiro, and Garret (2003) generated an adaptation of this instrument for European Portuguese changing the questions and the Likert scale to assess the way individuals feel about the activities (e.g. 0=unable; 1=lots of difficulty; 2=difficulty; 3=No difficulty) (Martins et al., 2003). Since this is an alteration of the original instrument, we asked the authors of the original instrument to culturally adapt a new Portuguese version, which was granted. The version we used was translated in EP with some minor adaptations made to some wording and expression to be culturally relevant for Portugal, following international guidelines (Beaton, Bombardier, Guillemin, & Ferraz, 1998; Guillemin, Bombardier, & Beaton, 1993; Hutchinson, Bentzen, & Konig-Zahn, 1997; Wild et al., 2005). It is awaiting validation. It is otherwise equivalent to the original instrument.

[1] Available from the advanced Communication and Swallowing Assessment (ACSA) http://acsa.web.ua.pt platform

3.2.2.2.2. Barthel Index, Portuguese version [2]

The BI was developed to measure functional ability in ADL of adults with neuromuscular or muscular-skeletal disorders (e.g. stroke, spinal cord injuries, rheumatoid arthritis, or amputations). It is composed of 10 subtest items that include: feeding; moving from wheelchair to bed and return; personal grooming; getting on/off the toilet; bathing; walking or propelling a wheelchair; stair climbing; dressing and undressing; bowel; and bladder control (see Appendix H). Subtests scoring range is zero to 15 with increments of five. The maximum total score is 100 and represents the highest level of independence. Lower scores represent greater dependency. The rating scale is completed by an observer or obtained by verbal reports from patients, carers and staff. This instrument is sensitive, has concurrent and predictive validity, is reliable, and has high internal validity (Mahoney & Barthel, 1965; Shinar et al., 1987; Sinoff & Ore, 1997). We asked the authors to culturally adapt this measure, which was granted. The version used was translated in EP with some minor adaptations made to some wording and expression to be culturally relevant for Portugal, following MAPI institute guidelines. It is then equivalent to the original instrument The remaining validation process is being undertaken.

3.2.2.2.3. Mini-Mental State Modificado, Portuguese version[1]

In this study we used the Mini-Mental State Modificado (MMSM), Portuguese version (Matos & Jesus, 2011b) of the Language Modified Mini-Mental State (LMMS) by Pashek (2008). The Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) has been demonstrated to be a valid and reliable measure for cognitive assessment of older people. The areas assessed by this instrument are: orientation; registration; attention; calculation; recall; language; and figure copying. The instructions are presented orally and the answers are also expected to be conveyed orally (Folstein et al., 1975; Tombaugh & McIntyre, 1992). Pashek (2008) created a language-modified version (LMMS) that included contextual support and multiple-choice response options, which could be used by PWA. Items such as orientation, auditory-verbal recall (modified for visual recall), attention, language, figure copy subtests were modified to multiple-choice options (six options), written words, and/or picture support. Additionally, the language subtest was adapted for patients with hemiplegia since this subtest required the use of both hands and many PWA

[2] Available from the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID) http://www.proqolid.org

have hemiparesis or hemiplegia (Pashek, 2008). The Portuguese version used colour photos, while the original LMMS used black and white line drawings (Matos & Jesus, 2011b; Pashek, 2008).

Each item is scored as one if the answer is correct or zero if it is incorrect. The scoring range is zero to 30. Cognitive deficit is identified if the total score is less than 15 for non-educated people, less than 21 for people with one to 11 years of education, and less than 26 for those with more than 11 years of education (Matos & Jesus, 2011b).

3.2.2.2.4. Communication Disability Profile, Portuguese version[1]

The Communication Disability Profile (CDP) (see Appendix J) is an instrument that measures the impact of stroke and aphasia in PWA's activities, participation and emotional status according to their views. It enables the PWA to respond according to his perspective despite his access to written language using accessible pictures and culturally relevant pictorial rating scales (Swinburn & Byng, 2006). Its known psychometric properties are good for activities and participation (Cronbach's alpha>0.8; and Cronbach's alpha>0.7) and weaker for emotions (Cronbach's alpha=0.59) (Chue, 2008).

It has four subtests: Activities, Participation, External influences and Emotions with many items scored zero to four (five-point Likert scale, e.g. "during the last week how easy is it to talk to strangers"). The Activities subsection has 20 scored items regarding speech, communication, auditory comprehension, reading, and writing; the Participation subsection has 13 scored items regarding social participation; and Emotion has 14. The External influences are not scored, but the barriers and facilitators for the PWA are identified (e.g. "What helps?"). Subsections can be analysed and calculated independently. In this study Activities and Participation are analysed separately. Higher scores represent lower levels of activities and participation (Matos & Jesus, 2011a; Swinburn & Byng, 2006).

3.2.2.2.5. Lisbon Aphasia Assessment Battery

The participants were assessed with the Lisbon Aphasia Assessment Battery (LAAB) (Castro-Caldas, 1979; Damásio, 1973; Ferro, 1986) on fluency, naming, simple auditory comprehension and word repetition tasks to diagnose the type of aphasia and to determine the aphasia coefficient (see Appendix K). The fluency is classified according to type and level: fluent, non-fluent and within a range of zero to five. Higher values in the fluency or non-fluency scales

represent a better speech performance. The naming task involves 16 real world objects. If the subject names the object successfully the score is one; if he does it incorrectly the score is zero. Less than 16 points represents naming difficulties. The simple auditory comprehension task includes eight instructions. The minimum score is zero, the maximum is eight and the cut-off point for good simple auditory comprehension is seven. If the subject performs each task correctly at the first time the score is one, if not but does on a second chance, the score is 0.5. If it is performed incorrectly twice the score is zero. The repetition task is composed of 30 words. If the individual does it correctly the score is one, if he does not, the score is zero. The cut-off point for good repetition is 23. Type of aphasia is diagnosed based on fluency analysis, and naming, simple auditory comprehension and repetition difficulties. Aphasia coefficient is determined through the sum of all these results divided by four. The final result is transformed in a percentage (Castro-Caldas, 1979; Damásio, 1973; Ferro, 1986).

3.2.2.2.6. Carers' Assessment of Managing Index, Portuguese version

The Carers' Assessment of Managing Index (CAMI) assesses the coping strategies used by the caregivers and how useful they prove to be (Nolan, Keady, & Grant, 1995; Oyebode, 2003) (see Appendix L). It was developed by Nolan et al. (1995) and the version used in this study was the Portuguese version by Brito (2002) that showed good internal consistency (0.80) (Barbosa, Figueiredo, Sousa, & Demaind, 2011; Brito, 2002). It has 38 items divided into three categories: problem solving strategies; emotional-cognitive strategies; dealing with the consequences of stress. The answers are given in a four-point Likert scale whether they "do not apply", "apply but do not find helpful", "apply and find it quite helpful" or "apply and find it very helpful". Higher scores reveal more helpful strategies are used by participants (Barbosa et al., 2011; Brito, 2002).

3.2.2.2.7. Sociodemographic datasheet

A questionnaire was used to collect additional sociodemographic data regarding occupation, cohabitation, socioeconomic status, and sick leave from work by doctors' orders. The socioeconomic status was assessed using the European Society for Social, Opinion and Market Research (ESOMAR) indicators (Cabral, 1995a, 1995b; Reif, Marbeau, Quatresooz, & Vancraeynest, 1991) by asking the occupational group and educational level of the person with greater financial income for the family (Cabral, 1995a, 1995b; Reif et al., 1991). Regarding PWA,

they were additionally asked about speech and language therapy data (if they have or had speech and language therapy and for how long) (see Appendix M), and concerning caregivers, the additional questions were about the amount of time caregivers spent with the PWA (see Appendix N).

3.2.2.2.8. Interviewers' experience of using the WHOQOL-Bref tool

The data was collected by the researcher or the speech and language therapist working with the PWA (see section 3.2.2.3.). The interviewers assessing PWA were asked to complete a visual analogue scale from zero to 10 (0=easy or any help; 10=difficult or great amount of help) to analyse the experience of using WHOQOL-Bref with PWA. Instruments should be easy to understand, to respond, and should be time efficient (Cruice, Hirsch, et al., 2000), so five questions were asked to the interviewers (see Appendix O): how easy it was for PWA to understand the WHOQOL-Bref; how easy it was to respond to the WHOQOL-Bref; the amount of help PWA needed; the overall use of the instrument; and the time spent with PWA to administer the WHOQOL-Bref.

3.2.2.3. Ethical and sampling procedures

Authorization for data collection was asked in 10 Portuguese institutions (north, centre, south of Portugal and islands): nine hospitals, and one rehabilitation centre attended by PWA. Before asking formally for authorization, a contact through telephone was made to make sure that those institutions attended by PWA. From those, six responded positively to our request (three in the north, one in the centre and two in the south of Portugal) (see Appendix P). Ethical approval was given by the ethics committees, the administrations and medical services directors of the institutions involved. Some cases were identified through independent speech and language therapists working in PWA's dwelling-place.

The data was collected all over the country by the researcher or by the local speech and language therapist (according to the rules and requirements of the institutions). All the documents were delivered personally by the researcher to the local speech and language therapist involved in the study. All the instruments were shown, explained, and role-playing sessions were performed to practice the administration of instruments. Instruments were completed in the following order: LAAB, MMSM, WHOQOL-Bref, WHOQOL-100 SR domain, CES-D,

BI, FAI, CDP, CAMI and sociodemographic datasheet. Every three weeks the researcher contacted the speech and language therapists to check the data collection progress or to clarify any queries.

Every set of documents for the speech and language therapists had a cover letter, a checklist of all the material (see Appendix Q) and a data sheet clarifying procedures (e.g. envelopes codification) (see Appendix R) and some general instructions for instruments use (e.g., the use of total communication if necessary, only) (see Appendix S).

All participants were given written information on the study (see Appendix T and U) that was read aloud by the speech and language therapist and written consent was obtained (see Appendix V and W). After answering to all the questions/instruments, all the information was sealed in coded envelopes according to the instructions given. The consent forms were kept in separate envelopes. Once completed, the questionnaires were returned to the researcher by the speech and language therapist.

3.2.2.4. Statistical Analysis

Data was analysed using SPSS 16.0 for Windows. Similar to study 1, as the WHOQOL-Bref scale is ordinal and the results of overall QOL are based on the responses of two questions (both in a five-point Likert scale), non-parametric tests were used. Descriptive statistics were used to characterise the QOL and SR of PWA and caregivers, as well as Spearman's rho coefficient that was used to measure the correlation between QOL and SR and: QOL domains; age; level of education; number of cohabitants; socioeconomic status; emotional status, time post stroke; aphasia coefficient; activities; participation; cognition; time after discharge, SLT time; time they left SLT and coping. The Kruskal-Wallis test was used to identify possible differences among QOL and SR according to: gender; living place; marital status; type of cohabitants; occupation; health status; type of motor impairment; aphasia etiology; having speech and language therapy currently or in the past. A regression analysis (stepwise method) was undertaken to identify which variables better explained overall QOL and SR (including life domains and SR WHOQOL items). The hierarchy boxes method was used in the linear regression to hierarchize the variables selected whether they were from the sample's significant correlations or from previous knowledge such as general population correlations results and/or literature. Correlations (Spearman's rho coefficient) and regression analysis were also used to verify the items of the SR domains that had stronger correlations with SR results, that better predicts it, and the SR domains that better explain overall QOL.

The Mann-Whitney test was used to compare groups' results (PWA, caregivers and control groups). First comparisons among groups were undertaken through visual inspection of the QOL and SR means. After that, a carefully matched sample was selected to do more feasible comparisons and to detect significant differences in the findings using the Mann-Whitney test. Acknowledging that is not appropriate to compare a sample of 255 with samples of 25 individuals, a smaller proportion of general population was selected to do comparisons. A data reduction procedure was designed matching age, gender, and educational level. All the subjects were analysed and those with the same characteristics of PWA and caregivers (concerning age, gender and educational level) were selected to two new and smaller groups of general population (from here on called 'control' groups). Whilst one-to-one matching is typically used, in this study 20% of the large sample was selected to maintain the heterogeneity in QOL data (variable of our concern). Fifty (50) healthy individuals were selected as PWA's control group and other 50 for the caregivers' control group. When the characteristics were not the same, the most similar individuals were selected. When we obtained more than two healthy participants per person with aphasia or per caregiver, a random technique was used to select the individuals to take part in the reduced sample.

Descriptive statistics were used to evaluate the experience of completing WHOQOL-Bref from speech and language therapists' perspectives of easy of understanding and responding, assistance required and length of administration.

CHAPTER 4: Results

This chapter is organised in topics according to study 1 (Portuguese general population sample), study 2 (PWA sample) and study 3 (caregivers sample) to facilitate navigation through the results, and to ensure organised presentation and statistical analysis. Given the amount of data of the studies and to facilitate navigation through the results some tables are shown in appendixes. The most important information of the tables in appendix is reported in the body of the text. The most relevant data tables were kept in this chapter.

4.1. Study 1 (Portuguese general population sample)

Participants were aged 25 to 84 years, with a mean age of 43 years. The majority of the participants was female (58%), had university level of education (37%), was employed (82%), was married or lived with a partner (69%), and reported themselves as healthy (91%) (see Table 9). The mean for emotional status of Portuguese general population was 12.38±8.10.

Table 9: Demographic data (N=255)

		Range	Mean ± SD
Age		25 - 84	42.65 ± 12.51
		n	**Percentage (%)**
Gender	Male	107	41.96
	Female	148	58.04
Educational level	Illiterate	3	1.17
	1-4 years	16	6.27
	5-6 years	14	5.49
	7-9 years	33	12.94
	10-12 years	68	26.67
	University	94	36.86
	Postgraduate	27	10.59
Occupation	Employed	209	81.96
	Unemployed	22	8.63
	Retired	24	9.41
Living Place	Mainland	212	83.14
	Islands	43	16.86
Marital status	Single	48	18.82
	Married/Partner	176	69.02
	Separated/Divorced	22	8.63
	Widow/widower	9	3.53

Table 9: Demographic data (N=255) (continued)

		n	Percentage (%)
Number of cohabitants	Alone	24	9.41
	1	79	30.98
	2	70	27.45
	3	66	25.88
	4	12	4.71
	5	4	1.57
Type of cohabitants	Alone	24	9.40
	Partner	66	25.90
	Partner & Children	103	40.40
	Parent(s)	23	9.00
	Other	39	15.30
Socioeconomic status	High	53	20.78
	Medium-high	97	38.04
	Medium	51	20.00
	Medium-low	32	12.55
	Low	22	8.63
Health*	Unhealthy	24	9.41
	Healthy	231	90.59

* Healthy and unhealthy status was determined by people responding to the WHOQOL-Bref's question "Are you currently ill?"; illness = unhealthy.

The majority of the sample was from Douro Litoral (13%) and Açores (12%) followed by Beira Litoral (10%) and Estremadura (9%) (see Table 10).

Table 10: Regional distribution (N=255)

Region*	Frequency	Percent	Valid Percent	Cumulative Percent
Minho	19	7.50	7.50	7.50
Trás-os-Montes	18	7.10	7.10	14.50
Douro litoral	32	12.50	12.50	27.10
Beira Alta	15	5.90	5.90	32.90
Beira Litoral	25	9.80	9.80	42.70
Beira Baixa	12	4.70	4.70	47.50
Ribatejo	13	5.10	5.10	52.50
Estremadura	24	9.40	9.40	62.00
Alto Alentejo	12	4.70	4.70	66.70
Baixo Alentejo	15	5.90	5.90	72.50
Algarve	23	9.00	9.00	81.60

Table 10: Regional distribution (N=255) (continued)

Region*	Frequency	Percent	Valid Percent	Cumulative Percent
Madeira	16	6.30	6.30	87.80
Açores	31	12.20	12.20	100.00
Total	255	100.00	100.00	

*Regions are presented by geographical order

4.1.1. Quality of life of Portuguese general population

In general, participants considered their QOL as good (mean=71.81) and scored highest in the physical domain, followed by psychological, SR and environmental domains. All the domains are qualitatively classified as "good" (see Table 11).

Table 11: Overall QOL and domains' means

	N	Range	Mean	Std. Deviation
Overall QOL	255	25-100	71.81	14.85
Physical domain	255	17.86-100	76.09	13.49
Psychological domain	255	20.83-100	74.44	13.35
SR domain	255	33.33-100	73.69	15.28
Environmental domain	255	34.38-100	66.30	12.04

Regarding the influence of QOL domains, every domain correlated significantly with overall QOL and the one that had the higher correlation was the physical domain (ρ=0.56, p=0.000) followed by psychological (ρ=0.50, p=0.000) and environment (ρ=0.45, p=0.000) domains, all of them with moderate associations. The SR domain had a weak but significant correlation with overall QOL (ρ=0.34, p=0.000) (see Appendix X, table X.1). The correlation between overall QOL and the WHOQOL-100 SR domain is also statistically significant and weak (ρ=0.37; p=0.000) (see Appendix X, Table X.2), however it is marginally stronger than its Bref SR domain counterpart.

Regarding overall QOL and demographic variables correlations, overall QOL had a weak but significant and negative correlation with age (ρ=-0.27, p=0.000), socioeconomic status (ρ=-0.14,

p=0.024) and emotional status (ρ=-0.34, p=0.000), and positive with educational level (ρ=0.33, p=0.000). Younger people had better QOL, as well as people with higher levels of education, higher socioeconomic status and less depressive symptoms. The number of cohabitants (ρ=0.02, p=0.817) and gender (χ^2=0.75) did not correlate with overall QOL (See Appendix X, Tables X.3 and X.4).

People living in the mainland and islands had significantly different QOL, as well as people with different marital status, different type of cohabitants, different occupations, and health status (see Table 12).

Table 12: Kruskal-Wallis test results for overall QOL and living place, marital status, type of cohabitants, occupation and health

		Overall QOL
Living place	Chi-Square	8.088
	Df	1
	Asymp. Sig.	0.004
Marital Status	Chi-Square	17.905
	Df	5
	Asymp. Sig.	0.003
Type of cohabitants	Chi-Square	9.75
	Df	4
	Asymp. Sig.	0.045
Occupation	Chi-Square	7.049
	Df	2
	Asymp. Sig.	0.029
Health	Chi-Square	29.436
	Df	1
	Asymp. Sig.	0.000

Single people had better overall QOL than the other marital status groups (see Table 13). People living with parents showed better overall QOL scores; the other groups had quite similar mean scores. People living on the islands had better QOL than those who lived on the mainland. People who were employed had better QOL than unemployed and retired participants. Retired individuals had the worst or lowest QOL. Healthy people had much better QOL scores than the unhealthy group (see Table 13).

The reader will also note on Table 13 that, although there is no significant gender correlation with QOL, females had better QOL results than males. The age group with better QOL was the youngest (24-44 years). People with better emotional health also had higher QOL means. People with postgraduate educational level had better QOL than the other educational level groups.

Regarding socioeconomic status, the group designated as “High” had the best overall QOL scores and those with “Low” socioeconomic status had the worst QOL (see Table 13).

Regarding QOL domains, the physical domain had the highest scores among almost all groups and the environment the lowest. The psychological domain was scored the highest for males, participants with seven to nine years of education/schooling, those separated/divorced, those living with partner, and those retired. The SR domain was scored the highest for illiterate and unhealthy groups; and the physical domain was scored the lowest by these same two sub-groups (see Table 13). It should be acknowledge that illiterate and widower subgroups have small numbers (illiterate n=3, widower n=9) and this may influence the results.

Table 13: Overall QOL and domains' descriptive data

			Overall QOL		Physical Domain		Psychological Domain		SR Domain		Environmental Domain	
		n	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Gender	Male	107	71.38	15.83	75.57	14.98	**76.25**	12.36	72.74	15.76	*66.06*	12.74
	Female	148	72.13	14.14	**76.47**	12.35	73.14	13.92	74.38	14.94	*66.47*	11.55
Age	25-44 (years)	150	73.58	14.95	**77.24**	12.92	75.31	12.86	75.00	15.02	*66.67*	12.84
	45-64 (years)	90	71.11	13.07	**75.63**	12.41	74.49	13.34	72.59	15.16	*65.94*	10.82
	64-84 (years)	15	58.33	17.47	**67.38**	21.21	65.56	15.79	67.22	17.39	*64.79*	11.23
Emotional status	Good	210	73.33	14.32	**78.03**	12.69	77.44	10.93	76.31	13.22	*67.74*	11.51
	Depressive Symptoms	45	64.72	15.38	**67.06**	13.62	60.46	14.77	61.48	18.23	*59.58*	12.33
Educational level	Illiterate	3	37.50	17.68	*41.07*	32.83	43.75	2.95	**58.33**	35.36	50.00	13.26
	1-4 years	16	64.84	13.09	**72.32**	13.71	66.93	10.70	66.15	14.10	*65.63*	7.82
	5-6 years	14	58.93	20.47	69.90	14.61	**73.21**	13.45	70.24	11.65	*60.71*	10.59
	7-9 years	33	68.94	14.70	73.70	14.28	**73.99**	9.32	72.47	14.66	*62.50*	12.40
	10-12 years	68	70.77	14.74	**76.58**	12.38	74.57	16.10	73.65	16.39	*64.75*	12.03
	University	94	75.00	12.02	**77.28**	13.09	75.18	12.57	75.09	15.29	*68.18*	73.03
	Postgraduate	27	80.09	12.62	**82.01**	9.37	79.48	10.40	77.47	13.04	*73.03*	11.83
Socioeconomic status	High	53	72.41	15.18	**76.95**	12.44	75.08	14.09	74.21	16.53	*70.17*	12.55
	Medium-high	97	74.23	12.34	**77.47**	13.01	76.07	12.94	75.34	14.28	*67.40*	12.29
	Medium	51	71.57	15.43	**76.19**	13.71	74.67	14.19	73.86	14.14	*64.71*	10.50
	Medium-low	32	68.75	13.85	**74.00**	13.85	72.92	13.05	73.18	16.50	*62.89*	10.93
	Low	22	64.77	16.33	**70.78**	16.33	67.42	9.93	65.53	15.91	*60.80*	11.64
Marital status	Single	48	79.43	13.76	**80.28**	12.39	76.13	12.89	74.83	16.80	*67.58*	14.51
	Married/Partner	176	70.17	14.57	**75.14**	13.12	73.67	13.52	73.25	14.95	*65.45*	11.37
	Separated/Divorced	22	69.89	16.21	75.00	17.36	**78.98**	12.43	75.76	16.04	*69.32*	12.30
	Widower	9	68.06	11.02	**75.00**	13.95	69.44	12.84	71.30	12.58	*68.75*	9.11

For overall QOL minimum and maximum underlined.

Across all domains and for each subgroup (male, female, …, parent(s), other) *minimum* values in italic and **maximum** values in bold.

Table 13: Overall QOL and domains' descriptive data (continued)

			Overall QOL		Physical Domain		Psychological Domain		SR Domain		Environmental Domain	
		n	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Type of cohabitants	Alone	24	71.88	14.86	**78.57**	16.08	75.35	13.23	78.47	15.13	*70.05*	11.40
	Partner	66	70.64	14.12	74.57	15.00	**74.62**	14.11	73.74	15.90	*68.28*	11.99
	Partner & Children	103	70.27	14.12	**74.90**	12.15	73.58	12.38	72.49	14.47	*63.96*	11.22
	Parent(s)	23	80.98	14.04	**81.83**	14.12	78.99	13.32	78.62	13.01	*71.06*	13.98
	Other	39	72.44	17.01	**76.92**	11.47	73.18	14.62	70.94	16.98	*64.02*	11.99
Living Place	Mainland	212	70.70	14.80	**75.02**	13.63	73.51	13.01	72.80	15.23	*65.83*	11.97
	Islands	43	77.33	13.98	**81.40**	11.55	79.07	14.19	78.10	14.89	*68.60*	12.25
Occupation	Employed	209	72.97	14.41	**76.95**	12.46	75.30	13.14	74.96	14.58	*66.58*	12.20
	Unemployed	22	69.32	14.80	**76.30**	15.29	72.54	13.53	68.56	19.40	*63.49*	10.58
	Retired	24	64.06	16.61	68.45	18.08	**68.75**	13.96	67.36	15.13	*66.41*	11.99
Health	Unhealthy	24	55.21	15.60	*56.10*	13.91	66.84	16.09	**70.83**	20.71	62.89	13.77
	Healthy	231	73.54	13.69	**78.17**	11.65	75.23	12.82	73.99	14.63	*66.65*	11.82

For overall QOL minimum and maximum underlined.

Across all domains and for each subgroup (male, female, …, parent(s), other) *minimum* values in italic and **maximum** values in bold.

In the presence of all WHOQOL-Bref domains, overall QOL was better predicted by the physical domain (37.5%), followed by the psychological domain (together they predicted 42.4%). The SR domain was not a significant predictor of overall QOL for the Portuguese general population sample (see Table 14).

Table 14: QOL domains as predictors of overall QOL

Linear regression (stepwise)			ANOVA(d)			
Model	R	R Square	Model	df	F	Sig.
1	0.612a	0.375	1	1; 253	151.623	0.000a
2	0.652b	0.424	2	2; 252	92.933	0.000b
3	0.664c	0.441	3	3; 251	65.883	0.000c

a. Predictors: (Constant), Physical domain
b. Predictors: (Constant), Physical domain, Psychological domain
c. Predictors: (Constant), Physical domain, Psychological domain, Environmental domain
d. Dependent Variable: Overall QOL

Among age, emotional status, educational level, socioeconomic status, and number of cohabitants, emotional status was the best predictor of QOL, explaining 13% of the variance of QOL results. This variable, along with educational level and age, altogether, explained 25% of overall QOL results. Socioeconomic status was not considered a significant predictor of QOL (see Table 15).

Table 15: Demographic predictors of overall QOL

Linear Regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.358a	0.128	1; 253	37.281	0.000
2	0.475b	0.226	2; 252	36.741	0.000
3	0.500c	0.250	3; 251	27.840	0.000

a. Predictors: (Constant), Emotional status
b. Predictors: (Constant), Emotional status, Education level
c. Predictors: (Constant), Emotional status, Education level, Age
d. Dependent variable: Overall QOL

4.1.2. Social relationships of Portuguese general population

The results of Portuguese general population sample revealed that they are satisfied with their SR (Mean=73.69) as shown in Table 11.

Age (ρ=-0.15, p=0.021), educational level (ρ=0.16, p=0.012) and emotional status (ρ=-0.45, p=0.000) influenced SR satisfaction of Portuguese general population. All these correlations were also verified with the SR domain of WHOQOL-100, although slightly higher values were obtained.

Socioeconomic status (p=0.082; p=0.053) and number of cohabitants (p=0.475; p=0.962) do not correlate with any SR domain (see Table 16).

People living in the mainland or islands (p=0.013) had significantly different satisfaction with their SR, as well as people with different occupations (employed, unemployed and retired) (p=0.042) (see Table 17). Looking at Table 13 we can see that people living in the islands (mean=78.10) and people that are employed (mean=74.96) were more satisfied with their SR.

Table 16: SR domains correlations

Correlations (Spearman's rho)			
		SR WHOQOL-Bref	**SR WHOQOL-100**
Age	Correlation Coefficient	-0.145*	-0.203**
	Sig. (2-tailed)	0.021	0.001
	N	255	255
Education Level	Correlation Coefficient	0.158*	0.214**
	Sig. (2-tailed)	0.012	0.001
	N	255	255
Socioeconomic Status	Correlation Coefficient	-0.109	-0.121
	Sig. (2-tailed)	0.082	0.053
	N	255	255
Number of cohabitants	Correlation Coefficient	-0.045	-0.003
	Sig. (2-tailed)	0.475	0.962
	N	255	255
Emotional Status	Correlation Coefficient	-0.454**	-0.526**
	Sig. (2-tailed)	0.000	0.000
	N	255	255

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 17: Kruskal-Wallis test results for SR of WHOQOL-Bref and living place, marital status, type of cohabitants, occupation and health

		SR WHOQOL-Bref
Living place	Chi-Square	6.120
	Df	1
	Asymp. Sig.	0.013
Marital status	Chi-Square	2.951
	Df	5
	Asymp. Sig.	0.708
Type of cohabitants	Chi-Square	8.544
	Df	4
	Asymp. Sig.	0.074
Occupation	Chi-Square	6.333
	Df	2
	Asymp. Sig.	0.042
Health	Chi-Square	0.042
	Df	1
	Asymp. Sig.	0.838

From all the variables studied (age, educational level, socioeconomic status, number of cohabitants and emotional status), emotional status and age were the best predictors of SR satisfaction. Emotional status explained 24% of variance in SR results. Together, emotional status and age explain 26% of overall results (See Appendix X, Table X.5)

Both SR domains were introduced in a linear regression model. In the presence of WHOQOL-100 RS, the WHOQOL-Bref SR domain was not considered a significant predictor of QOL (even though correlations shown are similar: SR WHOQOL-Bref ρ=0.34, p=0.000; SR WHOQOL-100 ρ=0.37, p=0.000). WHOQOL-100 SR predicted 13% of overall QOL. This regression analysis is significant (p=0.000) (see Appendix X, Table X.6).

All the items of WHOQOL-Bref SR domain had a significant and strong correlation with the domain overall results. The item with highest correlation was item 21 (How satisfied are you with your sex life?) (ρ=0.82, p=0.000), followed by item 22 (How satisfied are you with the support you get from your friends?) (ρ=0.77, p=0.000), and item with the lowest correlation coefficient was item 20 (How satisfied are you with your personal relationships?) (ρ=0.76, p=0.000). Although, the strength of the correlations is very similar, especially regarding items 22 and 20 (see Appendix X, Table X.7).

Concerning WHOQOL-100 SR domain correlations, every item had a significant correlation (strong to moderate) with the overall results of the domain. The items with the strongest correlations were: item 10 (How satisfied are you with your ability to provide for or support others?) (ρ=0.81, p=0.000); item 5 (To what extent can you count on your friends when you need them?) (ρ=0.72, p=0.000); item 9 (How satisfied are you with the support you get from your friends?) (ρ=0.72, p=0.000) (see Table 18). From these questions, only item 9 is part of WHOQOL-Bref (item 22).

Table 18: SR WHOQOL-100 domain total score and its items correlation

Correlations (Spearman's rho)							
		WHOQOL-100 SR Domain	**Item 1**	**Item 2**	**Item 3**	**Item 4**	**Item 5**
WHOQOL-100 SR Domain	Correlation Coefficient	1	0.589**	0.607**	0.556**	0.658**	0.719**
	Sig. (2-tailed)	.	0.000	0.000	0.000	0.000	0.000
	N	255	255	255	255	255	255
Item 6	Correlation Coefficient	0.663**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 7	Correlation Coefficient	0.690**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 8	Correlation Coefficient	0.668**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 9	Correlation Coefficient	0.716**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 10	Correlation Coefficient	0.814**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 11	Correlation Coefficient	0.677**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					
Item 12	Correlation Coefficient	0.684**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	255					

** Correlation is significant at the 0.01 level (2-tailed)
Items 6, 7 and 9 take part in WHOQOL-Bref

Regarding SR predictors, item 21 (How satisfied are you with your sex life?) of the WHOQOL-Bref predicts 67% of the variance of overall SR WHOQOL-Bref results, followed by item 22 (How

satisfied are you with the support you get from your friends?), and together both items explain 90%. All regression analysis were significant (p=0.000) (see Appendix X, Table X.8).

Among the 12 items of WHOQOL-100 SR, item 10 (How satisfied are you with your ability to provide for or support others?) strongly predicted WHOQOL-100 SR results (67%), followed by item 7 (How satisfied are you with your sex life?), item 5 (To what extent can you count on your friends when you need them?), item 11 (Do you feel happy about your relationship with your family members?), and item 1 (How alone do you feel in your life?). Together, these five items, explained 95% of the variance of WHOQOL-100 SR results. All regression analyses were significant (p=0.000) (see Appendix X, Table X.9).

4.1.3. Brief summary of study 1 results:

People from Portuguese general population consider their QOL as good and are satisfied with their SR. Age, socioeconomic status, educational level and emotional status are significantly correlated with overall QOL; living in mainland or islands, marital status, type of cohabitants, occupation and health status also seem to influence QOL; and emotional status is the best predictor of QOL.

Age, educational level and emotional status are also significantly correlated with SR results; and living in mainland or islands and different occupations also seems to influence SR satisfaction. Likewise for QOL, emotional status is the best predictor for SR's satisfaction.

In the presence of WHOQOL-100 SR domain, the same domain of WHOQOL-Bref is not a predictor of Portuguese general population QOL.

4.2. Study 2 (People with aphasia sample)

The PWA were aged 20 to 71 years, with a mean age of 54 years. The majority were male (52%), had one to four or 10 to 12 years of education (24% each), were retired (52%), were married or had a partner (84%), lived with the partner and children (40%), were from a medium-low socioeconomic status (48%), and reported themselves as healthy (96%). All PWA were from mainland, and the majority was from a region called Douro Litoral (52%) (see Table 19).

Table 19: PWA sociodemographic data (N=25)

		Range	Mean ± SD
Age		20-71	54.00 ± 14.90
		n	**Percentage (%)**
Gender	Male	13	52.00
	Female	12	48.00
Educational level	Illiterate	1	4.00
	1-4 years	6	24.00
	5-6 years	4	16.00
	7-9 years	5	20.00
	10-12 years	6	24.00
	University	3	12.00
	Postgraduate	0	0.00
Occupation	Employed	7	28.00
	Unemployed	3	12.00
	Retired	13	52.00
	Volunteer	1	4.00
	Student	1	4.00
Living place	Trás-os-Montes e Alto Douro	2	8.00
	Douro Litoral	13	52.00
	Beira Litoral	2	8.00
	Alto Alentejo	5	20.00
	Algarve	3	12.00
Marital status	Single	3	12.00
	Married/Partner	21	84.00
	Separated/Divorced	1	4.00
	Widow/widower	0	0.00
Number of cohabitants	1	8	32.00
	2	8	32.00
	3	3	12.00
	4	4	16.00
	5	2	8.00
Type of cohabitants	Partner	7	28.00
	Partner & Children	10	40.00
	Parent(s)	1	4.00
	Sibling(s)	1	4.00
	Parent(s) & Sibling(s)	1	4.00
	Other	5	20.00

Table 19: PWA sociodemographic data (N=25) (continued)

		n	Percentage (%)
Socioeconomic status	High	3	12.00
	Medium-high	4	16.00
	Medium	3	12.00
	Medium-low	12	48.00
	Low	3	12.00
Health*	Unhealthy	1	4.00
	Healthy	24	96.00

* Healthy and unhealthy status was determined by people responding to the WHOQOL-Bref's question "Are you currently ill?"; illness = unhealthy.

The majority of the participants with aphasia had speech and language therapy at the time of data collection (76%) and had hemiparesis (64%). The diagnosis of aphasia were Anomic aphasia (24%), Conduction aphasia (24%), Broca's aphasia (24%) and Transcortical Motor aphasia (28%). They had a mean of 27 months post-stroke and an average of aphasia coefficient of 71.35 (see Table 20).

Table 20: PWA stroke and aphasia data

		n	Percentage (%)
Speech and language therapy	Currently	19	76.00
	Past	6	24.00
Motor impairment	Hemiparesis	16	64.00
	Sensibility	2	8.00
	No impairment	7	28.00
Type of aphasia	Anomic	6	24.00
	Conduction	6	24.00
	Broca	6	24.00
	Transcortical motor	7	28.00
		Range	**Mean ± SD**
Aphasia coefficient		42.50-97.60	71.35 ±16.80
Time post-stroke (months)		4-148	26.68 ± 31.79

4.2.1. Quality of life of people with aphasia

The PWA showed an average of QOL between "bad" and "neither good nor bad" (mean=41), which is lower than for Portuguese general population (mean=72). The QOL domain with the lowest score was the SR, followed by the physical and psychological domain. The domain with the highest score was the environment. All the domains were qualitatively classified as "neither satisfied nor dissatisfied" (see Table 21).

Table 21: Overall QOL and domains' means for PWA

	N	Range	Mean	Std. Deviation
Overall QOL	25	0-75	41.00	27.37
Physical domain	25	14.29-89.29	50.71	23.12
Psychological domain	25	16.67-87.50	53.00	23.31
SR domain	25	0-91.67	50.67	25.90
Environmental domain	25	18.75-87.50	57.38	18.24

All QOL domains were significantly correlated with overall QOL. All the correlations were strong. The physical domain had the strongest correlation (ρ=0.87, p=0.000) and the SR domain the weakest (ρ=0.79, p=0.000), although still strong (see Table 22). All the correlations are stronger than those verified for Portuguese general population and for the caregivers.

Table 22: PWA overall QOL correlations with QOL domains (WHOQOL-Bref)

Correlations (Spearman's rho)					
		Physical	**Psychological**	**SR**	**Environment**
Overall QOL	Correlation Coefficient	0.870**	0.829**	0.787**	0.853**
	Sig. (2-tailed)	0.000	0.000	0.000	0.000
	N	25	25	25	25

** Correlation is significant at the 0.01 level (2-tailed)

Concerning the correlation between overall QOL and the WHOQOL-100 SR domain, it was statistically significant and strong (ρ=0.72, p=0.000) (see appendix y, Table Y.1) but a little lower than the one observed for the same domain of WHOQOL-Bref (ρ=0.79 p=0.000) (see Table 22).

The QOL of PWA was significantly correlated with emotional status (ρ=-0.56, p=0.003) and education level (ρ=0.46, p=0.021). The correlation with emotional status is negative and moderate, which means that the higher the depressive symptoms the worse the QOL (see Table 23). Regarding education level, the higher the education level, the better the QOL. These correlations were stronger than those of Portuguese general population group. The other sociodemographic variables studied did not correlate significantly with QOL.

Table 23: PWA overall QOL correlations with age, educational level, socioeconomic status, number of people living with and emotional status

Correlations (Spearman's rho)						
		Age	**Education Level**	**Socioeconomic Status**	**Number of cohabitants**	**Emotional Status**
Overall QOL	Correlation Coefficient	0.157	0.459*	-0.328	-0.303	-0.563**
	Sig. (2-tailed)	0.455	0.021	0.11	0.14	0.003
	N	25	25	25	25	25

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

The Kruskal-Wallis test revealed that there were no differences in overall QOL regarding gender (p=0.457), marital status (p=0.964), type of cohabitants (p=0.955), occupation (p=0.344) and health (p=0.182) for PWA (see Appendix Y, Table Y.2).

Overall QOL of PWA was additionally significantly correlated with the activities measured by the BI (ρ=0.55, p=0.005), FAI (ρ=0.68, p=0.000), CDP activities (ρ=-0.73, p=0.000), and CDP participation (ρ=-0.77, p=0.000) of PWA. The correlations were strong to moderate and revealed that the more activities or participation the PWA were involved in, the better their QOL. The strongest correlation was with participation (see Table 24).

Table 24: PWA correlations of overall QOL with: time post-stroke, aphasia coefficient, activities (BI, FAI and CDP), participation (CDP) and cognition (MMSM)

Correlations (Spearman's rho)					
		Overall QOL	**Time post-stroke**	**Aphasia coefficient**	**Activities (BI)**
Overall QOL	Correlation Coefficient	1	0.123	0.224	0.548**
	Sig. (2-tailed)	.	0.558	0.281	0.005
	N	25	25	25	25
Activities (FAI)	Correlation Coefficient	0.680**			
	Sig. (2-tailed)	0.000	-	-	-
	N	25			
Activities (CDP)	Correlation Coefficient	-0.728**			
	Sig. (2-tailed)	0.000	-	-	-
	N	25			
Participation (CDP)	Correlation Coefficient	-0.767**			
	Sig. (2-tailed)	0.000	-	-	-
	N	25			
Cognition (MMSM)	Correlation Coefficient	0.342			
	Sig. (2-tailed)	0.094	-	-	-
	N	25			

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

PWA's overall QOL did not correlate with the time they were discharged from hospital (p=0.508), with speech and language therapy time (p=0.343) or the time they stopped speech and language therapy (p=0.231) (see Appendix Y, Table Y.3). The Kruskal-Wallis test also revealed that there are no differences in overall QOL regarding the type of motor impairment (p=0.087), aphasia etiology (p=0.462) and currently having speech and language therapy or finished speech and language therapy (p=0.107) (see Appendix Y, table Y.4).

Regarding domains as QOL predictors, the physical domain was the best predictor of PWA's overall QOL (76%), followed by the environmental domain (together they explain 81%) (see Appendix Y, Table Y.5).

For PWA, in the presence of WHOQOL-Bref SR domain, the same domain of the WHOQOL-100 is not a predictor of overall QOL. In this linear regression, the WHOQOL-Bref SR domain explains 61% of the variance of overall QOL results (see Appendix Y, Table Y.6).

Considering the significantly correlated variables with PWA's and Portuguese general population's QOL, as well as the variables significantly correlated with PWA's QOL described in the literature (educational level, emotional status, activities measured by BI, FAI and CDP, participation, age, socioeconomic status and time post-stroke), we used a linear regression with a three block method. From all these variables, participation explained 55% of the results, followed by emotional status, and together explained 63%. Participation was the strongest predictor (see Appendix Y, Table Y.7).

4.2.2. Social relationships of people with aphasia

The average of PWA's SR showed that PWA are "neither satisfied nor dissatisfied" with their SR (mean=51) as can be seen in Table 21, which is a lower result than for Portuguese general population (mean=74). SR domains of both WHOQOL-Bref and WHOQOL-100 had significant correlations with emotional status (Bref SR ρ=-0.42, p=0.037; 100 SR ρ=-0.57, p=0.003), BI activities (Bref SR ρ=0.45, p=0.025; 100 SR ρ=0.49, p=0.014), FAI activities (Bref SR ρ=0.60, p=0.001; 100 SR ρ=0.66, p=0.000); CDP activities (Bref SR ρ=-0.67, p=0.000; 100 SR ρ=-0.68, p=0.000), and participation (Bref SR ρ=-0.71, p=0.000; 100 SR ρ=-0.70, p=0.000). WHOQOL-100 SR domain correlated additionally with aphasia coefficient (Bref SR ρ=0.40, 100 SR p=0.049). The better the emotional state, the more activities and the more participation, the higher the satisfaction with SR. Individuals with higher language functioning also have higher levels of

satisfaction with SR. The strongest correlation was with the variable participation (see Table 25). The SR domain of both instruments did not correlate significantly with age (Bref SR p=0.31; 100 SR p=0.625), educational level (Bref SR p=0.059; 100 SR p=0.053), socioeconomic status (Bref SR p=0.16; 100 SR p=0.33) or number of cohabitants (Bref SR p=0.253; 100 SR p=0.219) (see Appendix Y, Table Y.8). Furthermore, time after discharge (p=0.97; p=0.831), duration of speech and language therapy (p=0.45; p=0.270) and the time they left speech and language therapy (p=0.22; p=0.544), did not correlate to any of the SR domains (see Appendix Y, Table Y.9).

Table 25: PWA correlations of overall SR domains (WHOQOL-Bref and WHOQOL-100) and: time post-stroke, emotional status, aphasia coefficient, activities (BI, FAI and CDP), participation and cognition

Correlations (Spearman's rho)						
		WHOQOL-Bref SR	**WHOQOL-100 SR**	**Time post-stroke**	**Emotional Status**	**Aphasia coefficient**
WHOQOL-Bref SR	Correlation Coefficient	1	0.901**	0.023	-0.419*	0.367
	Sig. (2-tailed)	.	0.000	0.912	0.037	0.071
	N	25	25	25	25	25
WHOQOL-100 SR	Correlation Coefficient	0.901**	1	0.062	-0.576**	0.398*
	Sig. (2-tailed)	0.000	.	0.769	0.003	0.049
	N	25	25	25	25	25
Activities (BI)	Correlation Coefficient	0.447*	0.485*			
	Sig. (2-tailed)	0.025	0.014	-	-	-
	N	25	25			
Activities (FAI)	Correlation Coefficient	0.602**	0.659**			
	Sig. (2-tailed)	0.001	0.000	-	-	-
	N	25	25			
Activities (CDP)	Correlation Coefficient	-0.667**	-0.683**			
	Sig. (2-tailed)	0.000	0.000	-	-	-
	N	25	25			
Participation (CDP)	Correlation Coefficient	-0.711**	-0.704**			
	Sig. (2-tailed)	0.000	0.000	-	-	-
	N	25	25			
Cognition (MMSM)	Correlation Coefficient	0.322	0.295			
	Sig. (2-tailed)	0.117	0.152	-	-	-
	N	25	25			

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

For both the WHOQOL-Bref and WHOQOL-100 SR domains, no differences were found regarding gender (Bref SR p=0.85; 100 SR p=0.354), marital status (Bref SR p=0.41; 100 SR p=0.248), type of cohabitants (Bref SR p=0.71; 100 SR p=0.417), occupation (Bref SR p=0.27; 100

SR p=0.233), health (Bref SR p=0.26; 100 SR p=0.532), motor impairment (Bref SR p=0.40; 100 SR p=0.199), aphasia etiology (Bref SR p=0.98; 100 SR p=0.808) or currently having speech and language therapy or not (Bref SR p=0.95; 100 SR p=0.848) (see Appendix Y, Table Y.10).

To determine the predictors of PWA's SR, the variables that correlated with PWA's and general population's SR were considered (emotional status, activities measured by BI, FAI, and CDP, CDP participation, age and educational level). The variable that better explains the variance of the results was the participation (47%), followed by age (together explained 58%) (see Appendix Y, Table Y.11).

As shown previously, the WHOQOL-Bref SR domain is a better predictor of overall QOL result in PWA's group (61%) than the same domain of the WHOQOL-100.

The WHOQOL-Bref item with the highest correlation with the SR domain was item 22 (How satisfied are you with the support you get from your friends?) (ρ=0.92, p=0.000), followed by item 21 (How satisfied are you with your sex life?) (ρ=0.86, p=0.000) and item 20 (How satisfied are you with your personal relationships?) (ρ=0.81, p=0.000). All the correlations were significant and strong (see Appendix Y, Table Y.12).

Regarding WHOQOL-100 SR items, the greatest correlations were those observed for items 6 (How satisfied are you with your personal relationships?) (ρ=0.89, p=0.000), item 9 (How satisfied are you with the support you get from your friends?) (0.87, p=0.000) and item 5 (To what extent can you count on your friends when you need them?) (ρ=0.86, p=0.000). The item with the weakest correlation was item 2 (How well are your sexual needs fulfilled?) (ρ=0.57, p=0.007) (see Appendix Y, table Y.13).

A linear regression with WHOQOL-Bref items showed that item 22 (How satisfied are you with the support you get from your friends?) explained 87% of SR results, followed by item 21 (How satisfied are you with your sex life?) (together explained 94%) and item 20 (How satisfied are you with your personal relationships?) (all explained 99%) (see Appendix Y, Table Y.14).

Concerning WHOQOL-100 SR domain, the best predictors were items 5 (To what extent can you count on your friends when you need them?) (79%), followed by item 3 (Are you bothered by any difficulties in your sex life?) (92%) and item 6 (How satisfied are you with your personal relationships?) (all explained 94%) (see Appendix Y, Table Y.15).

4.2.3. People's with aphasia and Portuguese general population's overall quality of life and social relationships comparisons

To better compare our PWA results with Portuguese general population (control sample) we used a procedure to reduce the control sample to 50 individuals as similar as possible to PWA sample regarding gender, age and educational level. The same procedure was undertaken for caregivers.

As a result of this procedure, the demographic data of the new group is shown in Table 26. The data of PWA is also shown in order to facilitate the comparison among samples. Gender is equally distributed and age and educational level have similar results (see Table 26). There are no significant differences regarding age (p=0.840) and educational level (p=0.814) for these samples (see Appendix Y, Tables Y.16 and Y.17).

Table 26: Descriptive statistics of the control group and PWA group

		Control group (N=50)		PWA (N=25)	
		n	**%**	**n**	**%**
Gender	Male	26	52.00	13	52.00
	Female	24	48.00	12	48.00
		Range	**Mean ± SD**	**Range**	**Mean ± SD**
Age		25-84	54.70 ± 13.75	20-71	54.00 ± 14.90
Education Level		1-7	4.74 ± 1.45	1-7	4.68 ± 1.57

The Mann-Whitney test showed that there were significant differences among groups concerning overall QOL (p=0.000), and SR (p=0.0025) (see Table 27). PWA were less satisfied with their QOL, and with their SR than Portuguese general population (see Table 28).

Table 27: Mann-Whitney test results for overall QOL and SR comparison between groups (control and PWA)

Overall QOL	Mann-Whitney U	300.5
	Wilcoxon W	625.5
	Z	-3.729
	Asymp. Sig. (One-tailed)	0.000
SR WHOQOL-Bref	Mann-Whitney U	376
	Wilcoxon W	701
	Z	-2.823
	Asymp. Sig. (One-tailed)	0.0025

a. Grouping Variable: Group

Table 28: Descriptive statistics for overall QOL, and SR domain

	Control group (N=50)		PWA (N=25)	
	Range	Mean ± SD	Range	Mean ± SD
Overall QOL	25-87.5	66.25 ± 16.02	0-75	41.00 ± 27.27
SR WHOQOL-Bref	33.33-100	69.83 ± 15.42	0-91.67	50.67 ± 25.90

4.2.4. People's with aphasia experience of completing the WHOQOL-Bref from speech and language therapists' perspectives of easy of understanding and responding, assistance required, and length administration

Five speech and language therapists, including the researcher, administered the testing packs of instruments across the 25 PWA and reported their subjective ratings of ease of administration in a zero to 10 visual analogue scale. The results show that speech and language therapists reported the WHOQOL-Bref easy to use with PWA of this sample. The use overall was actually very easy (1.79 ± 2.10); with some individuals almost no help was needed (0.20) but with some a medium help was needed (5.00). It took an average of 14 minutes to administer, with a minimum of seven minutes and a maximum of 20 minutes (see table 29).

Table 29: Speech and language therapists' experience with WHOQOL-Bref

WHOQOL-Bref use	n	Range	Mean ± SD
Understanding	25	0.20-5	2.21 ± 1.35
Answering	25	0.50-5.90	2.12 ± 1.50
Help needed	25	0.20-5	2.41 ± 1.54
Use overall	25	0-6.50	1.79 ± 2.10
Time spent (minutes)	25	7-20	13.76 ± 4.32

4.2.5. Brief summary of the results of study 2:

In average, PWA had a "bad" or "neither good nor bad" QOL and were "neither satisfied neither dissatisfied" with their SR. Their QOL and SR were worse than those of people from general population. QOL was significantly correlated to emotional status, educational level, activities (BI, FAI and CDP), and CDP participation. Participation was the best predictor of PWA's QOL.

SR was significantly correlated with emotional status, activities (BI, FAI and CDP), CDP participation, and aphasia coefficient. Participation was the best predictor of PWA's SR.

WHOQOL-Bref SR domain was a better predictor of overall PWA's QOL than the same domain of WHOQOL-100.

4.3. Study 3 (Caregivers sample)

The caregivers' sample was aged 26 to 73 years, with a mean age of 51 years. The majority was female (68%), had 10 to 12 years of education (36%), was employed (64%), was married or lived with a partner (76%), lived with the partner and children (40%), was from a medium-low socioeconomic status (48%) and reported themselves as healthy (92%). All of them lived in mainland and the majority lived in Douro Litoral (52%) as shown in Table 30.

Table 30: Caregivers' sociodemographic data

		Range	**Mean ± SD**
Age		26-73	51.4 ± 15.5
		n	**Percentage (%)**
Gender	Male	8	32.00
	Female	17	68.00
Educational level	Illiterate	0	0.00
	1-4 years	4	16.00
	5-6 years	2	8.00
	7-9 years	5	20.00
	10-12 years	9	36.00
	University	4	16.00
	Postgraduate	1	4.00
Occupation	Employed	16	64.00
	Unemployed	2	8.00
	Retired	7	28.00
	Volunteer	0	0.00
	Student	0	0.00
Living Place	Trás-os-Montes e Alto Douro	2	8.00
	Douro Litoral	13	52.00
	Beira Litoral	2	8.00
	Alto Alentejo	5	20.00
	Algarve	3	12.00
Marital status	Alone	0	0.00
	Single	3	12.00
	Married/Partner	19	76.00
	Separated/Divorced	2	8.00
	Widow/widower	1	4.00
Number of cohabitants	1	8	32.00
	2	8	32.00
	3	3	12.00
	4	4	16.00
	5	2	8.00

Table 30: Caregivers' sociodemographic data (continued)

		n	Percentage (%)
Type of cohabitants	Partner	7	28.00
	Partner & Children	10	40.00
	Children	1	4.00
	Sibling(s)	1	4.00
	Parent(s) & Sibling(s)	1	4.00
	Other	5	20.00
Socioeconomic status	High	3	12.00
	Medium-high	4	16.00
	Medium	2	8.00
	Medium-low	12	48.00
	Low	4	16.00
Health*	Unhealthy	2	8.00
	Healthy	23	92.00

* Healthy and unhealthy status was determined by people responding to the WHOQOL-Bref's question "Are you currently ill?"; illness = unhealthy.

4.3.1. QOL of PWA's caregivers

In average, the caregivers considered their QOL between "neither good nor bad" and "good" (mean=63) while Portuguese general population classified it as "good" (mean=72). The QOL domain with the lowest score was the SR, followed by the environment and psychological domain. The domain with the greatest score was the physical domain. All the domains were qualitatively classified as "neither satisfied nor dissatisfied" or "satisfied" (see Table 31).

Table 31: Overall QOL and domains' means for caregivers

	N	Range	Mean	Std. Deviation
Overall QOL	25	25-87.50	63.00	13.73
Physical domain	25	21.43-96.43	68.86	17.90
Psychological domain	25	25-87.50	66.83	15.70
SR domain	25	16.67-83.33	58.67	18.55
Environmental domain	25	31.25-84.38	59.38	15.22

Regarding the correlations between overall QOL and QOL domains in caregivers' sample, all the correlations were significant; the majority of the domains were moderately associated with overall QOL results. The domain with the greatest correlation was the environment (ρ=0.71, p=0.000) followed by the psychological domain (ρ=0.62, p=0.001). The weakest correlation was

with SR domain (ρ=0.47, p=0.017) (see Appendix Z, Table Z.1). These correlations were weaker than those found with PWA's sample. Overall QOL correlations of both WHOQOL-Bref (ρ=0.47; p=0.017) and WHOQOL-100 SR (ρ=0.46, p=0.024) domains were similar (see Appendix Z, Tables Z.1 and Z.2).

Overall QOL was significantly and positively correlated with age (ρ=0.46, p=0.02) and negatively with emotional status (ρ=-0.53, p=0.006), but was not correlated with educational level, socioeconomic status, number of cohabitants and coping as shown in Table 32. Correlations with age and emotional status were moderate and were stronger than those observed in general population. Educational level and socioeconomic status were correlated with overall QOL in Portuguese general population and PWA, but the same was not shown for caregivers. Age was correlated with caregivers' and Portuguese general population's QOL but not with PWA's QOL. Emotional status was correlated with overall QOL in the three groups.

Table 32: Caregivers' overall QOL correlations with age, educational level, socioeconomic status, number of people living with, emotional status and coping

Correlations (Spearman's rho)					
		Overall QOL	**Age**	**Education Level**	**Socioeconomic Status**
Overall QOL	Correlation Coefficient	1	0.461*	0.172	-0.253
	Sig. (2-tailed)	.	0.020	0.410	0.222
	N	25	25	25	25
Number of cohabitants	Correlation Coefficient	-0.252			
	Sig. (2-tailed)	0.223	-	-	-
	N	25			
Emotional Status	Correlation Coefficient	-0.530**			
	Sig. (2-tailed)	0.006	-	-	-
	N	25			
Coping	Correlation Coefficient	0.107			
	Sig. (2-tailed)	0.609	-	-	-
	N	25			

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

Although the analysis of the coping strategies used are not part of the aims of this study, when analysing Table Z.3 of Appendix Z it is interesting to notice that the coping strategies used and recognized as really helpful were the items 12 ("taking life one day at the time") and 25 ("believe in myself and in my ability to handle the situation"). The caregivers rarely used

strategies that found not to be helpful, although items 2 (“letting off steam in some way e.g. shouting, yelling or the like”) and 22 (“ignoring the problem and hope it will go away”) were reported as used.

The Kruskal-Wallis test revealed no significant differences in overall QOL with caregivers’ gender (p=0.086), marital status (p=0.365), type of cohabitants (p=0.781), occupation (p=0.572), and health (p=0.526) (see Appendix Z, Table Z.4). These results are quite similar to those of PWA. Testing the correlation of caregivers’ overall QOL with PWA variables (time post-stroke, aphasia severity, activities (BI, FAI, CDP), participation and cognition, time after discharge, speech and language therapy time and the time since finishing speech and language therapy), results showed significant correlations with activities (ρ=-0.46, p=0.02) and participation (ρ=-0.56, p=0.004), as measured by CDP (see Appendix Z, Tables Z.5 and Z.6). Caregivers’ overall QOL was not significantly different depending on motor impairment of the PWA (p=0.224), aphasia etiology (p=0.180), and having speech and language therapy currently or having finished it (p=0.461) (see Appendix Z, Table Z.7).

Using a linear regression model with all the WHOQOL-Bref domains, the psychological domain is the best predictor of caregivers overall QOL (54%) (see Appendix Z, Table Z.8). When introducing only the SR domains of both WHOQOL-Bref and WHOQOL-100 (as they are a core focus in this research) in the linear regression model, the WHOQOL-Bref SR domain was the best predictor (18%) of overall QOL (see Appendix Z, Table Z.9).

The variables introduced in caregivers’ QOL linear regression model were selected based on significant correlations identified in the current study alone regarding caregivers’ and Portuguese general population’s QOL (age, emotional status, activities measured by CDP, participation, educational level and socioeconomic status), as there is no existing research to consider. The results showed that participation of PWA was the best caregivers’ QOL predictor (predicted 31% of overall results), followed by caregivers’ age and emotional status. Altogether these variables explained 57% of the variance of caregivers’ QOL results (see Table 33).

Table 33: Caregivers' overall QOL predictors

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.558a	0.312	1; 23	10.420	0,004a
2	0.691b	0.477	2; 22	10.033	0,001b
3	0.753c	0.566	3; 21	9.143	0,000c

a. Predictors: (Constant), Participation (CDP)
b. Predictors: (Constant), Participation (CDP), Age
c. Predictors: (Constant), Participation (CDP), Age, Emotional Status
d. Dependent Variable: Overall QOL

4.3.2. Social relationships of people's with aphasia caregivers

In average, caregivers were "neither satisfied nor dissatisfied" with their SR (mean=59) as shown in Table 31. These results are lower than those of Portuguese general population (mean=74).

The number of cohabitants (ρ=-0.40, p=0.048) was negatively correlated with the satisfaction of the caregivers with their SR revealed by WHOQOL-Bref SR domain, wherein caregivers who lived with fewer people were more satisfied with their SR. The same variable was not correlated with WHOQOL-100 SR, but the p value is very close to 0.05 (p=0.059). This also happens with the socioeconomic status variable, but inversely, concerning the SR domains. In addition, the WHOQOL-100 SR domain correlated moderately with level of education (ρ=0.43, p=0.033), as shown in Table 34.

Table 34: SR domains correlations with age, educational level, socioeconomic status, and number of people living with for caregivers' group

Correlations (Spearman's rho)					
		Age	**Education Level**	**Socioeconomic Status**	**Number of cohabitants**
WHOQOL-Bref SR	Correlation Coefficient	0.090	0.229	-0.383	-0.399*
	Sig. (2-tailed)	0.669	0.271	0.059	0.048
	N	25	25	25	25
WHOQOL-100 SR	Correlation Coefficient	-0.096	0.428*	-0.513**	-0.383
	Sig. (2-tailed)	0.648	0.033	0.009	0.059
	N	25	25	25	25

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

For caregivers, the SR domains (WHOQOL-Bref and WHOQOL-100) also correlated significantly with their emotional status (Bref SR ρ=-0.48, p=0.015; 100 SR ρ=-0.55, p=0.005), and with variables of PWA: FAI activities (Bref SR ρ=0.51, p=0.009; 100 SR ρ=0.41, p=0.045), CDP

activities (Bref SR ρ=-0.42, p=0.038; 100 SR ρ=-0.53, p=0.007), and CDP participation (Bref SR ρ-0.56, p=0.003; 100 SR ρ=-0.59, p=0.002). Concerning these variables, the worse the caregiver emotional status, the less satisfied with SR; and the more the PWA activities and participation, the more the caregiver satisfaction with SR. The results for both SR domains were similar for these variables. In addition, the WHOQOL-100 SR domain correlated with aphasia coefficient (ρ=0.49, p=0.014). In this case, the higher the PWA coefficient (less severity), the better the caregivers' satisfaction with SR, as shown in Table 35.

Table 35: SR domains correlations with age, educational level, socioeconomic status, and number of people living with for caregivers' group

Correlations (Spearman's rho)						
		WHOQOL-Bref SR	**WHOQOL-100 SR**	**Time post-stroke**	**Emotional Status**	**Aphasia coefficient**
WHOQOL-Bref SR	Correlation Coefficient	1	0.755**	0.050	-0.482*	0.231
	Sig. (2-tailed)	.	0.000	0.812	0.015	0.267
	N	25	25	25	25	25
WHOQOL-100 SR	Correlation Coefficient	0.755**	1	0.008	-0.547**	0.485*
	Sig. (2-tailed)	0.000	.	0.968	0.005	0.014
	N	25	25	25	25	25
Activities (BI)	Correlation Coefficient	0.353	0.391			
	Sig. (2-tailed)	0.084	0.053	-	-	-
	N	25	25			
Activities (FAI)	Correlation Coefficient	0.514**	0.405*			
	Sig. (2-tailed)	0.009	0.045	-	-	-
	N	25	25			
Activities (CDP)	Correlation Coefficient	-0.417*	-0.525**			
	Sig. (2-tailed)	0.038	0.007	-	-	-
	N	25	25			
Participation (CDP)	Correlation Coefficient	-0.562**	-0.586**			
	Sig. (2-tailed)	0.003	0.002	-	-	-
	N	25	25			
Cognition (MMSM)	Correlation Coefficient	0.293	0.191			
	Sig. (2-tailed)	0.155	0.36	-	-	-
	N	25	25			

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Time after discharge (Bref SR ρ=0.02, p=0.942; 100 SR ρ=0.01, p=0.958), the time PWA had speech and language therapy (Bref SR ρ=0.27, p=0.185; 100 SR ρ=0.29, p=0.156) and the time since PWA finished speech and language therapy (Bref SR ρ=-0.58, p=0.306; ρ=0.60, p=0.285) did

not correlate with caregivers' SR domains (see Appendix Z, Table Z.10). Furthermore, no significant differences were found in caregivers' SR satisfaction regarding gender (Bref SR p=0.86; 100 SR p=0.726), marital status (Bref SR p=0.86; p=0.833), type of cohabitants (Bref SR p=0.81; 100 SR p=0.818), occupation (Bref SR p=0.97; 100 SR p=0.652), health (Bref SR p=0.76; 100 SR p=0.652), motor impairment (Bref SR p=0.81; 100 SR p=0.654), aphasia etiology (Bref SR p=0.56; 100 SR p=0.952), or currently having or had speech and language therapy previously (Bref SR p=0.16; 100 SR p=0.633) using both SR domains (see Appendix Z, Tables Z.11).

The variables used to determine the predictors of SR of the caregivers were those that correlated with their SR (number of cohabitants, emotional status, activities measured by FAI and CDP and participation) and additionally those that correlated with general population SR (age and educational level). The variable that better explained the variance of caregivers' SR results was the number of cohabitants (33%), followed by participation (together explained 56%) and emotional status. Altogether, these variables explain 64% of SR WHOQOL-Bref results (see Appendix Z, Table Z. 12).

The WHOQOL-Bref SR domain was a better predictor of overall QOL results in caregivers' group (18%) than the same domain of the WHOQOL-100 (see Appendix Z, Table Z.9).

For caregivers, the WHOQOL-Bref item with the highest correlation (ρ=0.90, p=0.000) with the SR domain was the number 22 ("How satisfied are you with the support you get from your friends?"), followed by item 20 ("How satisfied are you with your personal relationships?") (ρ=0.87, p=0.000), and item 21 ("How satisfied are you with your sex life?") (ρ=0.60, p=0.000). All the correlations were significant and strong (see Appendix Z, Table Z.13).

Regarding WHOQOL-100 SR items, the highest correlations were observed for with items 12 ("How would you rate your sex life?") (ρ=0.84, p=0.000), item 5 ("To what extent can you count on your friends when you need them?") (0.83, p=0.000) and item 7 ("How satisfied are you with your sex life?") (p=0.73, p=0.000) (see Table 36). Other items were also significant. The item with the weakest correlation (also non-significant) was item 1 ("How alone do you feel in your life?") (ρ=-0.28, p=0.180) (see Table 36).

Table 36: SR WHOQOL-100 items correlations for caregivers' group

Correlations (Spearman's rho)							
		SR WHOQOL-100	**Item 1**	**Item 2**	**Item 3**	**Item 4**	**Item 5**
SR WHOQOL-100	Correlation Coefficient	1	-0.277	0.666**	-0.704**	0.635**	0.830**
	Sig. (2-tailed)	.	0.18	0.000	0.000	0.001	0.000
	N	25	25	25	25	25	25
Item 6	Correlation Coefficient	0.704**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 7	Correlation Coefficient	0.793**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 8	Correlation Coefficient	0.727**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 9	Correlation Coefficient	0.754**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 10	Correlation Coefficient	0.565**					
	Sig. (2-tailed)	0.003	-	-	-	-	-
	N	25					
Item 11	Correlation Coefficient	0.706**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 12	Correlation Coefficient	0.842**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					

**Correlation is significant at the 0.01 level (2-tailed)
**Correlation is significant at the 0.05 level (2-tailed)

Item 22 (“How satisfied are you with the support you get from your friends?”) explained 81% of SR domain (WHOQOL-Bref) overall results, followed by item 21 (“How satisfied are you with your sex life?”) that together explained 96% (see Appendix Z, Table Z.14). In the WHOQOL-100 SR domain, the item that better explained its results was item 5 (“To what extent can you count on your friends when you need them?”) (67%), followed by item 12 (“How would you rate your sex life?”) (together explained 85%) and item 8 (“How satisfied are you with the support you get from your family?”) (altogether explained 91%) (see Appendix Z, Table Z.15).

Comparing the results of both SR domains in the three groups (Portuguese general population, PWA and caregivers), we can see that all the three facets (satisfaction with the SR with others, support they receive from others and sexual life) are important for their overall SR.

All of the WHOQOL-Bref items are strongly correlated and are consistent predictors of SR results in the three groups. Furthermore, in WHOQOL-100, items from the three facets appear as important in correlations or as predictors of overall WHOQOL-100 SR results.

WHOQOL-100 SR domain better predicts overall QOL in general population sample, however the WHOQOL-Bref domain is the one that better explains it in PWA's and caregivers' group.

Using the WHOQOL-100 SR domain with PWA and with caregivers, some items that are not included in the WHOQOL-Bref were important predictors or revealed very strong correlations with WHOQOL-100 SR overall results (items 3, 5, 8, and 12) ("Are you bothered by any difficulties in your sex life?"; "To what extent can you count on your friends when you need them?"; "How satisfied are you with the support you get from your family?"; "How would you rate your sex life?"). The most frequent one and the best predictor of SR for both samples was item 5 ("To what extent can you count on your friends when you need them?").

4.3.3. Overall quality of life and social relationships comparisons of caregivers, people with aphasia and Portuguese general population

Similarly to what was done in study 2, to better compare caregivers and Portuguese general population regarding QOL and SR means, we used a procedure to reduce the general population sample to 50 individuals as similar as possible to caregivers regarding gender, age, and educational level.

The demographic data of the caregivers and the reduced control group is shown in Table 37. The gender is equally distributed and age and educational level have similar results. No significant statistical differences were found for age (p=0.795) and educational level (p=0.847) for these samples (see Appendix Z, Tables Z.16 and Z.17). The following comparisons between caregivers and general population are undertaken with the reduced matched sample of general population (n=50).

Table 37: Descriptive statistics of the control group and caregivers' group

		Control group (N=50)		Caregivers (N=25)	
		n	**%**	**n**	**%**
Gender	Male	16	32.00	8	32.00
	Female	34	68.00	17	68.00
		Range	**Mean ± SD**	**Range**	**Mean ± SD**
Age		26-73	50.44 ± 13.84	26-73	51.36 ± 15.51
Education Level		3-8	5.36 ± 1.35	3-8	5.40 ± 1.41

Overall QOL was significantly different (p=0.029) between caregivers and general population, and furthermore, significant differences were noted concerning SR (p=0.011) (see Appendix Z, Table Z.18). The descriptive statistics presented in the following Table show that caregivers are less satisfied with their QOL and SR than the control group (see Table 38).

Table 38: Descriptive statistics for overall QOL, and SR domain for caregivers and its control group

	Control group (N=50)		Caregivers (N=25)	
	Range	**Mean ± SD**	**Range**	**Mean ± SD**
Overall QOL	37.50-100	68.75 ± 13.66	25-87.50	63.00 ± 13.73
SR WHOQOL-Bref	33.33-100	70.67 ± 16.26	16.67-83.33	58.67 ± 18.55

The descriptive statistics for the PWA and caregivers' groups are as follows in Table 39. These two groups are significantly different regarding age (p=0.542) and educational level (p=0.116) (see Appendix Z, Tables Z.19 and Z.20).

Table 39: Descriptive statistics of the PWA's and caregivers' group

		PWA (n=25)		Caregivers (n=25)	
		n	**%**	**n**	**%**
Gender	Male	13	53.00	8	32.00
	Female	12	48.00	17	68.00
		Range	**Mean ± SD**	**Range**	**Mean ±**
Age		20-71	54.00 ± 14,9	26-73	51,36 ± 15,51
Education Level		1-7	4,68 ± 1,57	3-8	5,40 ± 1,41

When comparing QOL of the PWA to caregivers, we could see that their QOL was significantly different (p=0.0025). The same was not observed for SR (p=0.160) (see Appendix Z, Table Z.21).

Looking at the descriptive statistics as shown in Table 40, we could see that PWA were less satisfied with their QOL than caregivers (with a mean 22 point difference in satisfaction) (see Table 40). Caregivers had higher mean SR satisfaction, but was not significantly different.

Table 40: Descriptive statistics for overall QOL, and SR domain for PWA and caregivers

	PWA (N=25)		Caregivers (N=25)	
	Range	**Mean ± SD**	**Range**	**Mean ± SD**
Overall QOL	0-75	41.00 ± 27.27	25-87.50	63.00 ± 13.73
SR WHOQOL-Bref	0-91.67	50.67 ± 25.9	16.67-83.33	58.67 ± 18.55

4.3.4. Brief summary of the results of study 3:

In average, caregivers classify their QOL between “neither good nor bad” and “good” and their SR as “neither satisfied nor dissatisfied”. QOL was correlated with age, emotional status, CDP activities and CDP participation. PWA’s participation was the best predictor of caregivers’ QOL. SR was significantly correlated with emotional status, number of cohabitants, level of education, FAI activities, CDP activities, CDP participation and aphasia coefficient. The best predictor of caregivers’ SR satisfaction was number of cohabitants.

The WHOQOL-Bref SR domain was a better predictor of overall PWA’s QOL than the same domain of WHOQOL-100.

Caregivers had worse QOL and SR satisfaction than Portuguese general population, they had better QOL than PWA, and the differences between PWA and caregivers in SR were not significant.

CHAPTER 5: Discussion

QOL study is a core important issue in the world, healthcare and aphasia rehabilitation, so evidence based empirically derived data is needed as foundation for understanding. While a negative effect of aphasia on QOL can be anticipated given the general aphasiology evidence base, population-based QOL instruments have not previously been used to report it on QOL and the use of them would enable comparisons with the broader population. The aim of this study was to determine the impact of aphasia in PWA's and their caregivers QOL using a population-based QOL measure. To our knowledge, this is the first empirical study of a large scale nature with Portuguese general population that includes people all over mainland and islands, the first Portuguese investigation that studies PWA's QOL and SR and the first study worldwide that studies the QOL and SR of PWA's caregivers identifying correlations and predictors for their QOL and SR.

Interactions among QOL, SR and the other variables will be discussed as follows in three sections with regards to general population, to PWA or to caregivers' studies. Whenever possible, the findings of this study will be compared with other WHOQOL-Bref studies and with Portuguese data. With regard to our clinical groups, comparisons will be undertaken with other PWA and PWA's caregivers' studies whenever possible; when not possible comparisons will only be made with stroke studies.

5.1. Quality of life of general population

Portuguese general population participants of this study consider their QOL as good. The current findings agree with research with normal older adults in Portugal (Canavarro et al., 2009; Serra et al., 2006) (note both studies are based on the same sample), and in adults in the United Kingdom (Bowling, 1995; Farquhar, 1995). The order of importance of the domains (physical, psychological, SR and environment; means range of 76 to 66) in the current study is in line with the findings from the Portuguese study of Serra et al. (2006), the Brazilian study of Fleck et al. (2000), the Danish study of Noerholm et al. (2004), and the multinational study of Skevington et al. (2004) (which did not include Portuguese participants). The ranges of the QOL domains of these studies were very similar (between 77 and 64), except for Fleck's et al. (2000) that had higher range scores for domains satisfaction (83-70). Portuguese domains findings were much higher than general population in Taiwan (Wang et al., 2006) but lower than life domains of

Canadians (Hawthorne, Herrman, et al., 2006), so they are much more satisfied with their life domains than Portuguese general population. The findings of Australian, Taiwan, Canadian and Norwegian adults are also different from the results of the current study wherein the domains were differently ordered in terms of highest to lowest raking domains (e.g. environment and psychological domains were the best scored domains) (Hawthorne, Herrman, et al., 2006; Kalfoss et al., 2008; Wang et al., 2006). All the sample sizes of these studies were composed of more than 315 individuals, whilst Fleck's et al. (2000) study was composed of 50 healthy participants (Fleck et al., 2000; Hawthorne, Herrman, et al., 2006; Noerholm et al., 2004; Serra et al., 2006; Skevington et al., 2004; Wang et al., 2006), so the higher scores from the Fleck et al. (2000) study should be considered with caution. Two other Brazilian studies with larger samples (n=751 and n=3574) differ from Fleck's et al. (2000) Brazilian findings (and from ours) wherein the domains mean ranges were larger (79-57) and the SR domain was the best scored (Cruz et al., 2011; Moreno et al., 2006). This suggests that Brazilians are more satisfied with their social network. In summary, people have different levels of satisfaction of QOL domains worldwide, but Portuguese population findings of this study are in line with some findings reported in the literature (Fleck et al., 2000; Noerholm et al., 2004; Skevington et al., 2004). Additionally, Portuguese population seems to be as similarly satisfied in 2006 as in 2014 when comparing the current findings with those of Serra et al. (2006).

Usually, the studies of general population QOL report data on QOL domains, overall QOL, and their associations to age, gender and health. They report less frequently on emotional status, educational level, living place, marital status, occupation and type of cohabitants as was studied in the current study (Canavarro et al., 2009; Cruz et al., 2011; Fleck et al., 2006; Fleck, Leal, et al., 1999; Fleck et al., 2000; Gameiro et al., 2010; Hawthorne, Herrman, et al., 2006; L. Leung & Lee, 2005; Serra et al., 2006; Skevington et al., 2004; Spagnoli et al., 2012; Wahl et al., 2004). This may be due to the fact that many studies on general population QOL were mainly focused in studying the psychometric properties of the instruments and thus only studying associations with few sociodemographic variables. Thus only fewer studies are available for contextualisation of the current findings.

QOL and age were significantly associated in this study of the Portuguese general population. Although the association was weak, younger ages were associated with better QOL. These findings are in line with those of Fleck, Louzada, et al. (1999), Hawthorne, Herrman, et al. (2006); Skevington et al. (2004) and Wahl et al. (2004), but not with those of Spagnoli et al. (2012) who

reports on Portuguese general population data. This may be due to the fact that Spagnoli et al. (2012) studied individuals with a limited age range of 25 to 50 years.

Significant associations were also observed for educational level, wherein people with higher levels of education reported better QOL, and in specific domains. These findings support those of Wang et al. (2006) and Wahl et al. (2004), although this latter study used a different QOL tool (QOLS-N). Portuguese people highest QOL domains are in physical and psychological. Other Portuguese research has also found a positive association and highest satisfaction for psychological QOL albeit on a different measure (WHOQOL-100) (Gameiro et al., 2010). Conversely, participants in Gameiro's et al. (2010) study were least satisfied with their physical domain, whereas participants in the current study were most satisfied. This difference could be explained by the use of a different measure or different sampling. Finally, whilst Portuguese most educated participants were most satisfied with their physical domain, Brazilians were most satisfied with their SR (Cruz et al., 2011), and this may be attributed to different culture and value systems despite the same language (two varieties: European Portuguese and Brazilian Portuguese).

Emotional status and QOL were also significantly related. The most relevant literature was consulted for comparisons and derive from Portugal, Brazil and Hong Kong; many other studies did not investigate this variable in general population sample (Fleck et al., 2000; K. F. Leung, Wong, Tay, Chu, & Ng, 2005; Serra et al., 2006). Current findings agree with Fleck et al. (2006), L. Leung and Lee (2005), and Serra et al. (2006), wherein people with better emotional status reported better QOL.

Socioeconomic status was also significantly associated with overall QOL, wherein people with higher socioeconomic levels reported higher QOL scores. This same finding was observed in the southern Brazilian general population (Cruz et al., 2011).

In the current study, islanders reported higher QOL than people living on the mainland. A similar pattern has been identified in an English relevant study wherein London rural citizens reported better QOL than city centre (Farquhar, 1995). Knowing that the largest Portugal cities are in the mainland, this agrees with the previously established findings even though Farquhar (1995) used a qualitative approach. Whilst Gameiro's et al. (2010) study makes claims regarding residential location, its data is on life domains and not overall QOL, so the reports within the paper do not enable comparisons to the current findings.

Overall QOL was also significantly different between marital status subgroups. In our study, single people had better QOL. This does not agree with Wahl et al. (2004), whose findings showed

that being married or living with a partner is associated to a better QOL (Wahl et al., 2004). Our data may be influenced by the fact that the majority of the single sample was young (as in Wahl et al.'s (2004) study), and younger people had better QOL. Regarding QOL domains, Gameiro et al. (2010) observed that divorced/separated and widower people had worse results and found no differences between single and married people, but these results are not for overall QOL whereas this was the focus of the current study. Regarding different types of cohabitants, the differences were significant and those who live with the parents had the best QOL. No literature was found to compare this data with. Again, this data could be influenced by age because the great majority of the sample (82%) that lived with parents was 25 to 34 years. Quality of life among employed, unemployed and retired people was also significantly different. Employed people had the best QOL and retired the worse. This data supports results previously published by Wahl et al. (2004), but may be also influenced by age since retired people are older. In this study there seems to be some interdependence of age (being young), marital status (being single), residential arrangement (living with parents), and occupation (being employed). This requires further investigation in future studies.

Regarding health status, significant differences were also found among the unhealthy and healthy groups, with the former reporting better QOL. This is in agreement with Fleck, Louzada, et al. (1999), Wahl et al. (2004), Hawthorne, Herrman, et al. (2006), Fleck et al. (2006), and Canavarro et al. (2009) findings.

In the current study, gender and cohabitant number had no association with QOL. The gender findings are similar to those from Molzahn et al. (2010), Brajša-Žganec et al. (2011), and Spagnoli et al. (2012), but not with those of Wahl's et al. (2004) wherein women had higher QOL than men. All domains' scores from male and female participants of the present study were higher than those shown by Gameiro et al. (2010) in Portugal (when comparing the same domains of WHOQOL-100), and by Cruz et al. (2011) in Brazil. Men in the current study reported higher QOL psychological satisfaction, whereas physical QOL was the best for women, and the worst domain was environment for both. Interestingly, the Portuguese study by Gameiro et al. (2010) identified the level of independence, followed by SR domain as the ones with the highest scores both for men and women, and environment as the lowest scored for men. Skevington's (2004) multi-centre study reported higher means for men's physical domains, and social for women's domains, and lower scores for environment (Skevington et al., 2004). Environment was consistently indicated as the area of life of least satisfaction in Portuguese studies, and in the multinational study of Skevington et al. (2004) (in which Portugal was not represented), but there are some

differences regarding the domains that people are more satisfied. The satisfaction with life domains may change over time and can be culturally influenced justifying the differences with Skevington's et al. (2004) findings. No data is available in literature about number of cohabitants and its interactions with QOL.

Additionally, this study showed that emotional status and educational level were the sociodemographics that best predicted QOL and that physical and psychological domains were the domains that better predicted QOL. Very rarely have studies identified QOL predictors, however Gameiro et al. (2010) identified that educational level was a good predictor of some QOL domains. Serra et al. (2006), did not identify predictors but showed that the physical and psychological domains had the strongest correlation with overall QOL (Serra et al., 2006). The weakest correlation was with the SR domain (Fleck et al., 2000; Serra et al., 2006). The same results were found in our study.

5.2. Social relationships of general population

The participants of the current study were satisfied with their SR, which aligns with existing Portuguese findings (Gameiro et al., 2010; Serra et al., 2006). The multicentre findings of Skevington et al. (2004), as well as Brazilian, Canadian, Norwegian, and Danish findings also corroborate the current findings (Cruz et al., 2011; Fleck et al., 2000; Hawthorne, Herrman, et al., 2006; Kalfoss et al., 2008; Moreno et al., 2006; Noerholm et al., 2004; Skevington et al., 2004); and all findings suggest that Taiwanese people are the least satisfied with their SR (neither satisfied neither dissatisfied) and all their QOL domains (Wang et al., 2006).

Regarding SR, in the present study, they were influenced by age, educational level and emotional status. People with younger ages, more years of education and better emotional status were more satisfied with their SR; and age and emotional status were its best predictors. No association with SR was found regarding socioeconomic status and number of cohabitants. WHOQOL tools SR interactions with sociodemographics are not fully investigated in literature, although Gameiro et al. (2010) found the same association for age, educational level, and socioeconomic status. This agrees with other relevant literature findings (Cruz et al., 2011; Noerholm et al., 2004; Skevington et al., 2004). No data was found in literature regarding number of cohabitants.

In the current study, the WHOQOL-100 better predicted Portuguese general population SR than the same domain of WHOQOL-Bref, and items 10 (ability to provide for or support others), 7

(sex life), 5 (count on friends), 11 (relationship with family) and 1 (loneliness) were the best predictors of SR overall results. From all these items, the 7 (sex life) is the only one that is included within the WHOQOL-Bref. No literature was found regarding these data, making any contextualisation of this finding difficult. Overall, it seems that the longer subscale is more informative and thus, when using the Bref subscale it may be missing the opportunity to tap into other areas (as found in the WHOQOL-100 SR domain) such as supporting others, relationship with friends and family, and loneliness. Moreover, the findings of this study showed that the SR of the WHOQOL-Bref was the domain with the weakest association to general population overall QOL results, which is in line with the literature and the only three items of this domain may contribute for this result (Hawthorne, Herrman, et al., 2006; Skevington et al., 2004; Wang et al., 2006)

5.3. Quality of life of people with aphasia

Our PWA's sample, classified their QOL between "bad" and "nor good nor bad" and the results showed that their QOL was significantly worse compared to Portuguese general population, and caregivers. A decreased QOL has been previously reported for people with aphasia (Bose et al., 2009; Hinckley, 1998; A. Manders et al., 2010; Ribeiro, 2008; Ross & Wertz, 2002, 2003) and with stroke (Astrom et al., 1992; Clarke et al., 2002; Haley et al., 2010; Jaracz & kozubsky, 2003; Jonsson et al., 2005; Niemi et al., 1988; Tobin, Hevey, Horgan, Coen, & Cunningham, 2008) but only the studies of Ross and Wertz (2002, 2003) used the same instrument of the current study with PWA. Moreover, participants of Ross and Wertz (2002, 2003) study are more satisfied with life (mean=72) than the sample of the current study (mean=41). The QOL of their non-brain injured sample is also much higher (mean=84) than QOL of Portuguese general population (mean=72) (Ross & Wertz, 2002).

In the present study individuals with aphasia had lower levels of satisfaction in all QOL domains than Portuguese general population; and furthermore, the order of life domains was different, where the life domain best scored by PWA was environment, and SR the worst. Comparing with general population, lower results for PWA's QOL and life domains were reported in literature (A. Manders et al., 2010; Ribeiro, 2008; Ross & Wertz, 2002, 2003). Domains comparison with Ross and Wertz's (2002, 2003) study is not possible as they did not report domains findings. Overall, studies with PWA identified many changes in communication, and SR (Bose et al., 2009; Cruice, Hill, et al., 2010; Zemva, 1999), which may explain the lower scores of

SR for our sample. In line with PWA's results of the present study, for people with stroke, S. Levasseur et al. (2005) found that relationships with family and friends is the most important domain, which ought to be taken into account when it is the less satisfied domain for PWA. SR will be further explored in the coming paragraphs. For our sample of Portuguese general population the order of domains satisfaction were slightly different (more satisfaction with the physical domain, followed by psychological, SR and environmental domains), which means that aphasia may change the way people are satisfied with their life areas, especially regarding SR, environment and physical domains. PWA are less satisfied with environment than general population, nevertheless environment turned to be the best scored domain by PWA when compared with the other QOL domains. Stroke consequences such as hemiparesis and aphasia and the resulting emotional changes may be the rationale for environment becoming the best scored and for the lower satisfaction with SR, physical and psychological domains.

For PWA, their emotional health, level of education, and involvement in activities and participation associates with their QOL. Better emotional status, higher levels of education, higher involvement in activities and participation were associated to higher levels of QOL; and participation and emotional status were the best QOL predictors. Emotional status (depression, and mental health) was identified as a great predictor or as influencing QOL by several studies with PWA (Cruice, Worrall, et al., 2010; Cruice et al., 2003; Hilari, Wiggins, et al., 2003) and people with stroke (Astrom et al., 1992; Clarke et al., 2002; Haley et al., 2010; Jaracz & kozubsky, 2003; Jonsson et al., 2005; Kim et al., 1999; King, 1996; Kong & Yang, 2006; Kranciukaite & Rastenyte, 2006; Mota & Nicolato, 2008; Niemi et al., 1988; Oliveira & Orsini, 2008), wherein people with better emotional status had higher levels of QOL. This seems to be a strong consistent finding. However, Martins (2006) did not find this correlation for Portuguese people with stroke, which can most likely be attributed to a different QOL (SIS) and different sample characteristics. Regarding educational level and QOL, Manders' (2010) results for PWA seem to support our findings, but there is evidence to the contrary from Engell's et al. (2003), and Ribeiro's (2008) results for the same population, and for Kim's et al. (1999) results for people with stroke (Engell et al., 2003; Kim et al., 1999; Ribeiro, 2008). Several methodological aspects may explain these findings: different instruments (ALQI and SAQOL-39), different distribution and representativeness in education levels (Engell et al. (2003) analysed two levels of education, Ribeiro (2008) analysed three and our study analysed seven different levels of education), and cultural differences may justify this different influence of educational level in QOL, as Engell et al. (2003) is German, Ribeiro (2008) is Brazilian, and Kim et al. (1999) is Canadian. One of the QOL

predictors (emotional status) was the same for PWA and Portuguese general population in the current study. These findings suggest that the presence of aphasia did not interfere with some core predictors of Portuguese citizens QOL.

QOL, activities and social participation associations were also shown in the current study; the less the engagement in activities and social participation, the worse was QOL. Regarding PWA, the studies report the loss of autonomy for many activities (Ross & Wertz, 2002; Zemva, 1999), including socialisation (Bose et al., 2009; Sarno, 1997), leading to less satisfaction with QOL (Hilari, Wiggins, et al., 2003). Independence, socialising and engaging in activities have major importance for those with aphasia to have a successful living (K. Brown, Worrall, Davidson, & Howe, 2010; Cruice et al., 2006). The activities are a core aspect that influence QOL (Cruice, Hill, et al., 2010). Current study's results are in line with these studies. According to stroke studies, socialisation, returning to work and participation in activities (daily living activities and/or leisure activities) decreases after stroke (Astrom et al., 1992; Clarke et al., 2002; Kim et al., 1999; Kranciukaite & Rastenyte, 2006; Labi, Phillips, & Greshman, 1980; Martins, 2006; Niemi et al., 1988; Oliveira & Orsini, 2008; Tobin et al., 2008), so their QOL might be affected. People with stroke with lower well-being are less satisfied with their activities of daily living (Clarke et al., 2002), and people with better QOL have higher levels of participation in activities (Mayo et al., 2002; Oliveira & Orsini, 2008; Patel et al., 2006). This last statement is also true for Portuguese aphasia participants. Furthermore, involvement in activities and participation association to QOL was observed in general population studies (Brajša-Žganec et al., 2011; M. Levasseur et al., 2008) where indicators of activity and participation were included in test batteries.

Sociodemographics such as age, gender, socioeconomic status, marital status, number and type of cohabitants, occupation and health did not significantly influence PWA QOL in our study. Age findings are in accordance with Hinckley (1998) for PWA, but not with Hilari, Wiggins, et al. (2003) and Ribeiro (2008), where the differences may be due to the use of different measures. Concerning people with stroke, most studies report no association with age (Astrom et al., 1992; Jonsson et al., 2005; Kong & Yang, 2006; Martins, 2006), however one study with much older participants did note a significant finding (Kim et al., 1999). According to the current study findings, gender is not associated with PWA's QOL (Engell et al., 2003; Hilari, Wiggins, et al., 2003; Ribeiro, 2008), or to people's QOL after stroke (Haan et al., 1995; Kim et al., 1999; Kong & Yang, 2006; Martins, 2006). The same had been previously observed for socioeconomic status, marital status, occupation and health of PWA by Hilari, Wiggins, et al. (2003) and Hinckley (1998). Other studies that have substantially older participants or different samples are not in line with the

results of the present study regarding marital status (Kim et al., 1999) and gender (Jonsson et al., 2005). With regard to cohabitants, Astrom et al. (1992) reported that living alone is associated to QOL in people with stroke. However we did not find this association to be significant, PWA living with few cohabitants have higher levels of QOL, which is in line with Astrom's et al. (1992) findings.

Cognition, motor impairment, time post-stroke, aphasia aetiology, aphasia severity (language functioning), the time PWA were discharged from hospital, and the aspects related to speech and language therapy (how long; time since finished, and currently having or having had speech and language therapy) did not influence the QOL of PWA in the current study. These findings agree with the literature regarding PWA's motor impairment (Hinckley, 1998), aphasia severity (Engell et al., 2003; Hinckley, 1998; Ross & Wertz, 2002) and time post stroke (Engell et al., 2003; Ribeiro, 2008). Hilari, Wiggins, et al. (2003) reported the influence of comorbidities in QOL, considering more than motor impairment, so comorbidities beyond motor impairment seem to influence the QOL of PWA (Hilari, Wiggins, et al., 2003), but motor impairment per se do not (Hinckley, 1998). Cognition is also a predictor of QOL according to Hilari, Wiggins, et al. (2003). The instrument used to collect this data (Raven Coloured Progressive Matrices), and the QOL instrument (SAQOL-39) may be the reasons for different findings (Hilari, Wiggins, et al., 2003). Regarding time post stroke Hinckley (1998) did not support our findings perhaps because the sample had much more time post stroke (mean=46 months). The time PWA were discharged from hospital, and the aspects related to speech and language therapy have not been previously reported in the literature. Concerning people with stroke, according to the current study findings, stroke type (Kim et al., 1999; Martins, 2006), and time post stroke (Kong & Yang, 2006) is not associated to QOL.

Age and socioeconomic status were associated both with PWA QOL and with Portuguese general population QOL. Additionally, marital status do not influence PWA's QOL as it seems to for Portuguese general population, as well as the type of cohabitants, occupation and general health. These findings may suggest that in the presence of aphasia other variables such as participation have more importance for QOL than age. However, we should acknowledge that these findings can be influenced by sample characteristics and size, for example, living place (mainland or islands) cannot be considered for our PWA because all the participants with aphasia lived in mainland.

5.4. Social relationships of people with aphasia

Participants with aphasia are less satisfied with SR than Portuguese general population and their caregivers. In fact, the social contacts tend to diminish after a stroke (Astrom et al., 1992; Martins, 2006) or aphasia for PWA (Bose et al., 2009; Zemva, 1999) and their caregivers (Zemva, 1999), but they are a great contributor for successful living (K. Brown et al., 2010; Cruice et al., 2006). Emotional status, activities and participation influence significantly the SR satisfaction of PWA and its greatest predictor is participation. This kind of data was not previously available in the literature, although, as emotional status, activities and participation seem to be important SR predictors, they should be assessed and addressed in interventions in order provide better levels of SR in these subjects.

There is no data available in the literature to compare the following findings, so these findings are discussed on their own merit. The findings of our study suggest that the Bref WHOQOL SR domain is more appropriate to assess PWA's QOL than its longer version from WHOQOL-100. These findings reveal that WHOQOL-Bref has good coherence and breadth for this clinical group, so that there is no need for additional questions. In fact, this domain showed a stronger association to overall QOL than the association observed for general population. WHOQOL-Bref is actually very easy to use with PWA with the characteristics of our sample and takes a very reasonable time to administer. These characteristics are indeed good usability indicators (Cruice, Hirsch, et al., 2000). In clinical practice, this instrument may assist clinicians in making judgments about the life areas most affected by disability and, according to this, making treatment decisions. Additionally, by facilitating the understanding of the impact of the disability in the clients lives the interaction between health professional and client may improve, be more comprehensive and the client may find his treatment more meaningful (WHO, 1996; WHOQOLGroup, 1993). To know more details about a client's life and their SR, an interview should be used.

5.5. Quality of life of the caregivers

This is the first study that studied PWA's caregivers QOL and reported their QOL between "neither good nor bad" and "good". Their QOL is significantly different (worse) than that of Portuguese general population, and better than that of PWA. In fact, there are great negative changes in caregivers of PWA's lives (Bakas et al., 2006; Cruice, 2007; Franzén-Dahlin et al., 2008; Grawburg et al., 2013a; Michallet et al., 2003; Nätterlund, 2010; Santos et al., 1999), but no studies with PWA's caregivers have data about their level of satisfaction with life. Great negative

changes are also observed in caregivers of people with stroke (C. Anderson et al., 1995; Bethoux et al., 1996; Blake & Lincoln, 2000; Blonder et al., 2007; Bugge et al., 1999; Exel et al., 2005; Jeng-Ru et al., 1998; Jonsson et al., 2005; Morimoto et al., 2003; Rombough et al., 2006; Scholte op Reimer et al., 1998; Tang & Chen, 2002), so aphasia and stroke seem to have a consistent negative influence on life satisfaction of the caregivers.

There are no published reports on caregivers QOL domains or predictors in aphasia so the findings are discussed on their own merit and analysed comparing to related findings available in literature. The findings of this study showed that the life domain with the greatest association with caregivers' QOL is the environment followed by psychological. The weakest association was with the SR domain. Having only three items of SR domain may contribute for this result regarding this domain (Hawthorne, Herrman, et al., 2006; Skevington et al., 2004; Wang et al., 2006). Moreover, SR is the domain where caregivers are less satisfied (SR will be further explored below). The best QOL domain predictor of PWA's caregivers QOL is the psychological domain. Emotional status is actually strongly associated to PWA's caregivers QOL, being its strongest predictor. Many caregivers of PWA report changes on their emotional status (Hemsley & Code, 1996; Howe et al., 2012; Kitzmuller et al., 2012; McGurk et al., 2011; Michallet et al., 2003; Nätterlund, 2010; Pound et al., 2001; Santos et al., 1999) so their QOL is strongly and negatively influenced by their emotional state. Knowing that emotional status is significantly associated with QOL, it is necessary to take into account and address it in order to improve caregivers' QOL. Many caregivers of PWA also report burden, need for support and respite (K. Brown et al., 2011; Denman, 1998; Kitzmuller et al., 2012; Michallet et al., 2003; Nätterlund, 2010; Pound et al., 2001), which might indicate that environment is not adequate for these people's support needs, and it might be also crucial for their QOL given the strong association with the environmental domain to QOL. Another important finding is that age of the caregiver and activities and participation of the PWA also influence significantly caregivers' QOL, so that working on PWA's activities and social participation may have a positive impact in caregivers' life satisfaction. Age is also a strong predictor of caregivers' QOL. Older caregivers had better QOL, which may have to do with their experience to cope with life challenges. The coping strategies most used by the caregivers were problem- and emotion-focused, e.g. problem solving, control of the significance of the problem, acceptance and reframing (McGurk et al., 2011; Michallet et al., 2003). Older caregivers may use these strategies more effectively and might be an important resource to help the younger caregivers.

5.6. Social relationships of the caregivers

Caregivers were less satisfied with SR than Portuguese general population, and more satisfied than PWA although the difference is not statistically significant. Another novel finding is that caregivers' SR are significantly influenced by socioeconomic status, number of cohabitants, emotional status of the caregiver, and activities and social participation of PWA. Number of cohabitants and emotional status were the best predictors of their SR. These findings suggest that caregivers living with fewer people are more satisfied with SR. It may be that living with fewer people may improve the quality of the interactions. The literature did not treat the data this way so it is not possible to make comparisons, but many changes in SR have been previously reported (Hemsley & Code, 1996; Kitzmuller et al., 2012; Le Dorze et al., 1996; Le Dorze et al., 2009; Michallet et al., 2003; Nätterlund, 2010; Pound et al., 2001; S. Williams, 1993). Comparing with the other samples of our study, emotional status seems to have great importance for SR, since it is strongly associated or predictive of the SR satisfaction of the three groups. Additionally, activities and participation of PWA seem to be crucial for both PWA's and caregivers' SR satisfaction. So these are important aspects to address and improve in order to promote the SR of both.

Overall, results show that aphasia and its language and communication consequences seem to impact negatively in PWA and caregivers QOL and SR satisfaction, since the satisfaction with their QOL and SR are much lower than Portuguese general population and depends on important variables linked to aphasia consequences such as communicative activities and social participation of the person with aphasia. Emotional status, activities and social participation seem to be core variables to improve both PWA and caregivers QOL and SR.

CHAPTER 6: Study limitations, future work and conclusions

6.1. Study limitations and future work

As limitations of the current study, the response rate (58%) of our Portuguese general population sample is an issue since we don't know the reasons for non-responding and whether the QOL of non-responders is similar to the responders'. The non-probability sampling method used is also a limitation, so the findings should be interpreted with caution. Nevertheless, individuals within this study are a reasonably close match to the Portuguese population characteristics for mean age and gender, and the effect sizes were small (correlation and regression) and medium (chi-square). More studies are needed in order to achieve reference values for this population allowing comparisons among other healthy or unhealthy populations. In order to achieve that, a representative and larger sample is desirable.

The size of PWA's and caregivers' samples is also an issue, as well as the fact that only PWA with good auditory comprehension were included. It is very challenging to measure outcomes for a representative group of PWA since not all persons can be recruited given the instruments used. This is an identified issue for PWA but also for people with stroke without aphasia (Mayo et al., 2002). Although we used an adequate sample size when comparing to other studies with PWA (Bose et al., 2009; Cruice, Hill, et al., 2010; Engell et al., 2003; Lata-Caneda et al., 2009; Ross & Wertz, 2003; Zemva, 1999) it is still not enough the make generalisations and to use statistics with more power. Therefore the results from PWA's and caregivers studies should be interpreted with caution too. A bigger and representative sample is desirable for future research. Additionally, more work should be done concerning QOL measures that are suitable for people with severe aphasia. It can be extremely difficult to facilitate the understanding and expression of people with severe aphasia, although all the efforts should be undertaken to make it possible, since they are frequently excluded from the studies and the communication impact on their lives should also be studied. Another study limitation is that the data collection was undertaken by different speech and language therapists because it may introduce some variations in administrating the instruments. However training before the data collection reduced this confounding factor. This method allowed more PWA and caregivers to participate all across the country and allowed an overall assessment about the usefulness of the WHOQOL-Bref by different speech and language therapists. In future research speech and language therapists may be asked to video record while administering new measures (such as CDP and WHOQOL-Bref) for the researcher to check on fidelity of new assessment administration.

The low reported QOL and SR, and emphasis in activities and participation of the PWA suggest that professionals should consider them when offering an intervention to PWA and caregivers. Activities and participation based rehabilitation programs and their impact on QOL and SR satisfaction can be the focus for future research.

More research is needed in this field. As we have seen, there are many studies with people with stroke, but the knowledge about the impact of the health condition in PWA's QOL is much more limited. The same was observed for PWA's caregivers. Different methodologies and instruments used in the studies difficult the comparison among all of them. Thus, common instruments methodology and variables studied are desirable to facilitate comparisons and generalisations as advocated by COMET initiative and recent published papers regarding the importance of core outcome measurements in aphasia (Brady et al., 2014; Hula, Fergadiotis, & Doyle, 2014; MacWhinney, 2014; Wallace, Worrall, Rose, & Le Dorze, 2014). WHOQOL-Bref seems to be an adequate tool to use with PWA moderately impaired, as well as the CDP that is a more comprehensive tool. More comprehensive and inclusive QOL assessment tools should be developed or adapted and used in intervention and research with PWA. Studies regarding the efficacy of treatments are also needed and QOL assessment may be very useful as an outcome measure. Social interventions, family centred and community-based programs (focused on activities, participation and QOL) with PWA and their caregivers should be undertaken in order to enhance their SR and QOL satisfaction.

6.2. Conclusions

In the current study PWA and their caregivers are less satisfied with their QOL and SR than Portuguese general population, so aphasia seems to impact negatively in their QOL and SR satisfaction. Different variables have different impacts in peoples' lives concerning the three groups studied. Emotional status has great importance among the three groups concerning QOL and SR. Additionally, activities and participation of PWA have great impact in both PWA and caregivers' QOL and SR. Other variables (e.g., age, educational level, and socioeconomic status) revealed their influence in these two variables (QOL and SR) though they vary according to the group and the analysed variable. Emotional status, age and educational level are the best predictors of Portuguese general population's QOL. Emotional status and participation are the best predictors for PWA's QOL. Emotional status (of the caregiver), and activities and participation (of the PWA) are the best predictors for caregivers' QOL. Concerning SR, again, emotional status

and age are the best predictors for Portuguese general population; participation is the best SR satisfaction predictor for PWA; and emotional status and the number of cohabitants for the caregivers. These results are important to take into account to focus the assessment and the intervention in the important aspects of people's lives. Rehabilitation should focus on identifying those factors that foster or impede PWA participation in activities, as well as psychological assessment and counselling in order to provide adequate services to both (PWA and caregivers) and have greater impact in their SR and QOL. Emotional status is a very important area to fulfil to help people having a better QOL, so clinicians should be vigilant and refer PWA to appropriate professionals whenever needed. Furthermore, clinicians should be very attentive to the level of activities and social participation of the PWA. They need to be assessed through measures such as the CDP and activities and participation related goals need to be integrated in rehabilitation in order to improve them and to promote PWA's and their caregivers' satisfaction with life and with SR. Impairment-based assessment and therapy should not be abandoned, but expansion of traditional practices ought to be encouraged to incorporate communication and social goals according to activities and participation needs, thus enhancing patients QOL. The perspective of patients own satisfaction with activities and participation is crucial, as well as the impact of them in their QOL and SR. WHOQOL-Bref captures individuals' own perception on their satisfaction with life so it is appropriate to be used by therapists in life assessment and therapy planning in aphasia. The use of the most satisfied areas of life to support and improve activities and participation of the PWA can be strategic and impactful in PWA's and their caregivers QOL and SR, as well as using activities and participation to work on the improvement of the areas of life less satisfied. PWA and caregivers should be involved and conscious of the aims and intervention planning so they can be more focused, motivated and collaborative in the rehabilitation program. The use of self-reported and life meaningful measures may facilitate this process. QOL assessment is also important to negotiate intervention methods and priorities with the team as the institutions want to provide services with the greatest positive impact possible in people lives with fewer resources. Speech and language therapy services are becoming less available since the financial resources are limited. PWA have less often the opportunity to take advantage of the SLT for the period of time they really need and in the places that are more appropriate to improve activities and participation. Moreover, people such as caregivers often do not come to hospitals. Therefore policies that outline the practices of speech and language therapy need to change if we want to address PWA and their caregivers QOL. Community based interventions may be crucial for that. When health services are not prepared to offer these services, it is recommended to do whatever

is needed to enhance the goal of facilitating PWA and their caregivers to have quality in their lives (Cruice et al., 2006). Each case is unique so the assessment and the intervention should be adequate and individualised. Knowing the variables that are more important for their lives is needed. This will obviously have greater chance of success when the whole rehabilitation team perceives their clients' QOL (Cruice, Hill, et al., 2010). Furthermore, QOL assessment is crucial in the definition, implementation and planning of health policies and to analyse the effects of policy changes, so the use of instruments such as the WHOQOL-Bref is recommended. Since it is population based cross-culturally developed instrument, clinicians, administrators and legislators can be confident on the sensitivity of the instrument and the results can be compared intra and inter individuals as well as across cultures and populations allowing a more comprehensive understanding of aphasia worldwide. Results of studies like this may contribute to converging opinions and practices.

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APPENDIXES

Appendix A: World Health Organization Quality of Life Scale - Bref (WHOQOL-Bref)

WHOQOL-BREF

ORGANIZAÇÃO MUNDIAL DE SAÚDE

FACULDADE DE MEDICINA DA UNIVERSIDADE DE COIMBRA
Coordenador: Prof. Doutor Adriano Vaz Serra (adrianovs@netvisao.pt)

FACULDADE DE PSICOLOGIA E DE CIÊNCIAS DA EDUCAÇÃO DA UNIVERSIDADE DE COIMBRA
Coordenadora: Prof. Doutora Maria Cristina Canavarro (mccanavarro@fpce.uc.pt)

	Equações para calcular a pontuação dos domínios	Resultados	Resultados transformados	
			4-20	0-100
Domínio 1	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 □ + □ + □ + □ + □ + □ + □			
Domínio 2	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) □ + □ + □ + □ + □ + □			
Domínio 3	Q20 + Q21 + Q22 □ + □ + □			
Domínio 4	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 □ + □ + □ + □ + □ + □ + □ + □			

DADOS PESSOAIS

A1	**Idade**		anos

A2	**Data de Nascimento**	____ / ____ / _____	

A3	**Sexo**		Masculino
			Feminino

A4	**Escolaridade**	Não sabe ler nem escrever	
		Sabe ler e/ou escrever	
		1º-4º anos	
		5º-6º anos	
		7º-9º anos	
		10º-12º anos	
		Estudos Universitários	
		Formação pós-graduada	

A5	**Profissão**	

A6.1	**Freguesia**	
A6.2	**Concelho**	
A6.3	**Distrito**	

A7	**Estado Civil**	Solteiro(a)	
		Casado(a)	
		União de facto	
		Separado(a)	
		Divorciado(a)	
		Viúvo(a)	

B1a Está actualmente doente? Sim ☐ Não ☐

B1b Que doença é que tem? _____

B2 Há quanto tempo? _____

B3 Regime de tratamento? Internamento ☐ Consulta Externa ☐ Sem tratamento ☐

C. Forma de administração do questionário

1. Auto-administrado ☐
2. Assistido pelo entrevistador ☐
3. Administrado pelo entrevistador ☐

D. Tem alguns comentários a fazer a este estudo?

_____

_____

_____

_____

_____

OBRIGADO PELA SUA AJUDA!

Instruções

Este questionário procura conhecer a sua qualidade de vida, saúde, e outras áreas da sua vida.

Por favor, responda a todas as perguntas. Se não tiver a certeza da resposta a dar a uma pergunta, escolha a que lhe parecer mais apropriada. Esta pode muitas vezes ser a resposta que lhe vier primeiro à cabeça.

Por favor, tenha presente os seus padrões, expectativas, alegrias e preocupações. Pedimos-lhe que tenha em conta a sua vida nas **duas últimas semanas**.

Por exemplo, se pensar nestas duas últimas semanas, pode ter que responder à seguinte pergunta:

	Nada	Pouco	Moderadamente	Bastante	Completamente
Recebe das outras pessoas o tipo de apoio que necessita?	1	2	3	4	5

Deve pôr um círculo à volta do número que melhor descreve o apoio que recebeu das outras pessoas nas duas últimas semanas. Assim, marcaria o número 4 se tivesse recebido bastante apoio, ou o número 1 se não tivesse tido nenhum apoio dos outros nas duas últimas semanas.

Por favor leia cada pergunta, veja como se sente a respeito dela, e ponha um círculo à volta do número da escala para cada pergunta que lhe parece que dá a melhor resposta.

		Muito Má	Má	Nem Boa Nem Má	Boa	Muito Boa
1 (G1)	Como avalia a sua qualidade de vida?	1	2	3	4	5

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
2 (G4)	Até que ponto está satisfeito(a) com a sua saúde?	1	2	3	4	5

As perguntas seguintes são para ver até que ponto sentiu certas coisas nas duas últimas semanas.

		Nada	Pouco	Nem muito nem pouco	Muito	Muitíssimo
3 (F1.4)	Em que medida as suas dores (físicas) o(a) impedem de fazer o que precisa de fazer?	1	2	3	4	5
4 (F11.3)	Em que medida precisa de cuidados médicos para fazer a sua vida diária?	1	2	3	4	5
5 (F4.1)	Até que ponto gosta da vida?	1	2	3	4	5
6 (F24.2)	Em que medida sente que a sua vida tem sentido?	1	2	3	4	5
7 (F5.3)	Até que ponto se consegue concentrar?	1	2	3	4	5
8 (F16.1)	Em que medida se sente em segurança no seu dia-a-dia?	1	2	3	4	5
9 (F22.1)	Em que medida é saudável o seu ambiente físico?	1	2	3	4	5

As seguintes perguntas são para ver **até que ponto** experimentou ou foi capaz de fazer certas coisas nas duas últimas semanas.

		Nada	Pouco	Moderadamente	Bastante	Completamente
10 (F2.1)	Tem energia suficiente para a sua vida diária?	1	2	3	4	5
11 (F7.1)	É capaz de aceitar a sua aparência física?	1	2	3	4	5
12 (F18.1)	Tem dinheiro suficiente para satisfazer as suas necessidades?	1	2	3	4	5
13 (F20.1)	Até que ponto tem fácil acesso às informações necessárias para organizar a sua vida diária?	1	2	3	4	5
14 (F21.1)	Em que medida tem oportunidade para realizar actividades de lazer?	1	2	3	4	5

		Muito Má	Má	Nem boa nem má	Boa	Muito Boa
15 (F9.1)	Como avaliaria a sua mobilidade [capacidade para se movimentar e deslocar por si próprio(a)]?	1	2	3	4	5

As perguntas que se seguem destinam-se a avaliar se se sentiu **bem ou satisfeito(a)** em relação a vários aspectos da sua vida nas duas últimas semanas.

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
16 (F3.3)	Até que ponto está satisfeito(a) com o seu sono?	1	2	3	4	5
17 (F10.3)	Até que ponto está satisfeito(a) com a sua capacidade para desempenhar as actividades do seu dia-a-dia?	1	2	3	4	5
18 (F12.4)	Até que ponto está satisfeito(a) com a sua capacidade de trabalho?	1	2	3	4	5
19 (F6.3)	Até que ponto está satisfeito(a) consigo próprio(a)?	1	2	3	4	5
20 (F13.3)	Até que ponto está satisfeito(a) com as suas relações pessoais?	1	2	3	4	5
21 (F15.3)	Até que ponto está satisfeito(a) com a sua vida sexual?	1	2	3	4	5
22 (F14.4)	Até que ponto está satisfeito(a) com o apoio que recebe dos seus amigos?	1	2	3	4	5
23 (F17.3)	Até que ponto está satisfeito(a) com as condições do lugar em que vive?	1	2	3	4	5
24 (F19.3)	Até que ponto está satisfeito(a) com o acesso que tem aos serviços de saúde?	1	2	3	4	5
25 (F23.3)	Até que ponto está satisfeito(a) com os transportes que utiliza?	1	2	3	4	5

As perguntas que se seguem referem-se à **frequência** com que sentiu ou experimentou certas coisas nas duas últimas semanas.

		Nunca	Poucas vezes	Algumas vezes	Frequentemente	Sempre
26 (F8.1)	Com que frequência tem sentimentos negativos, tais como tristeza, desespero, ansiedade ou depressão?	1	2	3	4	5

Appendix B: World Health Organization Quality of Life Scale – 100 (WHOQOL-100) Social Relationships domain

WHOQOL-100 – Domínio das Relações Sociais

As perguntas que se seguem foram extraídas do instrumento WHOQOL-100, domínio 4, e procuram conhecer a forma como classifica as suas **relações sociais**. Irá encontrar algumas perguntas às quais já respondeu no instrumento WHOQOL-Bref. É importante que responda novamente.

Na resposta às questões, considere as suas **duas últimas semanas.**

As perguntas seguintes destinam-se a avaliar até que ponto **experimentou** certas coisas nas duas últimas semanas. Ponha um círculo à volta do número correspondente à intensidade do que sentiu.

		Nada	Pouco	Nem muito nem pouco	Muito	Muitíssimo
1 (F13.1)	Até que ponto se sente só na vida?	1	2	3	4	5
2 (F15.2)	Em que medida são satisfeitas as suas necessidades sexuais?	1	2	3	4	5
3 (F15.4)	Sente-se incomodado por quaisquer dificuldades na sua vida sexual?	1	2	3	4	5

		Nada	Pouco	Moderadamente	Bastante	Completamente
4 (F14.1)	Recebe das outras pessoas o tipo de apoio que necessita?	1	2	3	4	5
5 (F14.2)	Em que medida pode contar com os seus amigos quando precisa deles?	1	2	3	4	5

As perguntas que se seguem destinam-se a avaliar se se sentiu **satisfeito(a), feliz ou bem** em relação a vários aspectos da sua vida nas duas últimas semanas. Ponha um círculo à volta do número que melhor traduz a maneira como se sente.

		Muito insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito satisfeito
6 (F13.3)	Até que ponto está satisfeito(a) com as suas relações pessoais?	1	2	3	4	5
7 (F15.3)	Até que ponto está satisfeito(a) com a sua vida sexual?	1	2	3	4	5
8 (F14.3)	Até que ponto está satisfeito(a) com o apoio que recebe da sua família?	1	2	3	4	5
9 (F14.4)	Até que ponto está satisfeito(a) com o apoio que recebe dos seus amigos?	1	2	3	4	5
10 (F13.4)	Até que ponto está satisfeito(a) com a sua capacidade de ajudar ou apoiar outras pessoas?	1	2	3	4	5

		Muito infeliz	Infeliz	Nem feliz nem infeliz	Feliz	Muito feliz
11 (F13.2)	Sente-se feliz com as suas relações familiares?	1	2	3	4	5

		Muito má	Má	Nem boa nem má	Boa	Muito boa
12 (F15.1)	Como avalia a sua vida sexual?	1	2	3	4	5

Appendix C: Center for Epidemiologic Studies Depression Scale (CES-D)

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)

(Gonçalves & Fagulha, 2004)

Encontra nesta página uma lista das maneiras como se pode ter sentido ou reagido. Indique com que frequência se sentiu dessa maneira **durante a semana passada** fazendo uma cruz no quadrado correspondente.

Use a seguinte chave: Nunca ou muito raramente (menos de 1 dia)
Ocasionalmente (1 ou 2 dias)
Com alguma frequência (3 ou 4 dias)
Com muita frequência ou sempre (5 ou 7 dias)

Durante a semana passada:	Nunca ou muito raramente	Ocasional-mente	Com alguma frequência	Com muita frequência ou sempre
1. Fiquei aborrecido com coisas que habitualmente não me aborrecem	☐	☐	☐	☐
2. Não me apeteceu comer; estava sem apetite	☐	☐	☐	☐
3. Senti que não conseguia livrar-me da neura ou da tristeza, mesmo com a ajuda da família ou dos amigos	☐	☐	☐	☐
4. Senti que valia tanto como os outros	☐	☐	☐	☐
5. Tive dificuldade em manter-me concentrado no que estava a fazer	☐	☐	☐	☐
6. Senti-me deprimido	☐	☐	☐	☐
7. Senti que tudo o que fazia era um esforço	☐	☐	☐	☐
8. Senti-me confiante no futuro	☐	☐	☐	☐
9. Pensei que a minha vida tinha sido um fracasso	☐	☐	☐	☐
10. Senti-me com medo	☐	☐	☐	☐
11. Dormi mal	☐	☐	☐	☐
12. Senti-me feliz	☐	☐	☐	☐
13. Falei menos do que o costume	☐	☐	☐	☐
14. Senti-me sozinho	☐	☐	☐	☐

15. As pessoas foram desagradáveis ou pouco amigáveis comigo	☐	☐	☐	☐
16. Senti prazer ou gosto na vida	☐	☐	☐	☐
17. Tive ataques de choro	☐	☐	☐	☐
18. Senti-me triste	☐	☐	☐	☐
19. Senti que as pessoas não gostavam de mim	☐	☐	☐	☐
20. Senti falta de energia	☐	☐	☐	☐

Appendix D: Sociodemogaphic datasheet for Portuguese general population

Dados Pessoais Adicionais

Por favor, preencha cada um dos espaços com uma cruz (x) ou com a informação solicitada.

1	**Nacionalidade**	

2	**Ocupação**	Empregado	
		Desempregado	
		Reformado	
		Voluntário	

3	**Habita com**	Sozinho	
		Cônjuge	
		Filho(s)	Com quantos filhos vive? _____
		Pai	
		Mãe	
		Irmão(ãos)	Com quantos irmãos vive? _____
		Sogro	
		Sogra	
		Nora	
		Genro	
		Outro(s)	Quais? _____ Quantas são as "outras" pessoas que vivem consigo? _____

Considere agora a **pessoa com maior rendimento no seu agregado familiar.** Coloque uma cruz (x) no grupo ocupacional a que essa pessoa pertence*.

4	**Grupo ocupacional**	Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 6 ou mais trabalhadores	
		Quadro superior (responsável por 6 ou mais trabalhadores)	
		Quadro superior (responsável por 5 ou menos trabalhadores)	
		Profissão liberal ou similar	
		Quadro médio (responsável por 6 ou mais trabalhadores)	
		Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 5 ou menos trabalhadores	
		Profissão técnica, científica e artística por conta de outrem	
		Quadro médio (responsável por 5 ou menos trabalhadores)	
		Empregado de escritório	
		Estudante, doméstica, inactivo	
		Empregado trabalhando sem ser em escritório	
		Trabalhador manual ou similar por conta própria	
		Desempregado	
		Trabalhador manual por conta de outrem	

*** *Nota:*** Caso a pessoa considerada tenha várias actividades, considere a actividade principal de onde resultam os rendimentos. Caso a pessoa seja reformada, considere a actividade ocupacional relativa à actividade que exercia antes de se reformar.

Vire a página, por favor.

Continue a considerar a pessoa **com maior rendimento no seu agregado familiar.**

5	**Escolaridade**	Não sabe ler nem escrever	
		Sabe ler ou escrever sem possuir diploma	
		1º Ciclo do Ensino Básico (antiga 4ª classe)	
		2º Ciclo do Ensino Básico (antigo 6º ano)	
		3º Ciclo do Ensino Básico (antigo 9º ano)	
		11º-12º Anos de escolaridade	
		Bacharelato ou frequência de curso superior	
		Licenciatura ou mais	

Muito Obrigada pela sua colaboração!

Appendix E: Ethics committee authorization for Portuguese general population's study

COMISSÃO DE ÉTICA

da **Unidade Investigação em Ciências da Saúde - Enfermagem** (UICISA-E)

da **Escola Superior de Enfermagem de Coimbra** (ESEnfC)

Parecer Nº 118-11/2012

Título do Projeto: Qualidade de vida da população portuguesa

Identificação do(s) Proponente(s)
Nome(s): Luís Miguel Teixeira de Jesus ; Ana Brígida Francisco Patrício
Filiação Institucional: Universidade de Aveiro
Investigador Responsável/orientador: Luís Miguel Teixeira de Jesus

Relator(es): Margarida Vieira

Parecer

Do estudo:

O estuco pretende determinar a forma como a população portuguesa em geral classifica a sua qualidade de vida e quais os preditores de qualidade de vida dessa população.

Os autores propõem-se realizar um estudo transversal correlacional, de janeiro a dezembro de 2013, com uma amostra de população portuguesa "com satisfação um nível de confiança de 95% e o intervalo de confiança de 5", calculada em 384 indivíduos, usando a técnica de amostragem em "bola de neve", podendo ser incluídas pessoas com mais de 25 anos, de nacionalidade portuguesa e residente em Portugal.

Refere-se que o estudo será realizado na Universidade de Aveiro e ali analisados os dados, destinando-se à obtenção do grau de doutor pelo segundo autor.

Os dados serão colhidos utilizando a versão portuguesa do World Health Organization Quality of Life Scale, versão abreviada (WHOQOL Bref, Serra et al., 2006) e a versão portuguesa do Center for Epidemiologic Studies Depression Scale (CES-D, Gonçalves & Fagulha, 2004) e ainda uma ficha de dados sociodemográficos. Não é referida autorização dos autores para a utilização dos instrumentos referidos.

Não são identificados riscos ou custos para os sujeitos e não existirá qualquer compensação. É garantida a confidencialidade dos dados em todo o processo e a inclusão voluntária dos sujeitos, incluindo na documentação informação a fornecer e modelo de consentimento.

Parecer:

Numa perspetiva exclusivamente ética, somos de parecer que nada há a opor ao estudo desde que obtido o assentimento dos autores dos instrumentos de colheita de dados que se pretende utilizar.

O relator: _____

Date: 12 / 11 / 12 O Presidente da Comissão de Ética: _____

Appendix F: Study information (Portuguese general population)

Exmo(a) Sr(a),

Estamos a solicitar a colaboração de pessoas para participarem na realização de um estudo sobre a qualidade de vida das pessoas com afasia e dos seus familiares. Se tem mais de 25 anos, vive em Portugal e tem nacionalidade portuguesa, por favor, participe.

Este estudo tem uma finalidade científica e académica, destinando-se à obtenção do grau de Doutor de Ana Brígida Francisco Patrício. Intitula-se "Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares" e é supervisionado pelo Professor Doutor Luís Miguel Teixeira de Jesus da Universidade de Aveiro e pela Professora Doutora Madeline Cruice da City University.

No âmbito desta investigação é necessário recolher dados através de questionários. A análise desses dados vai permitir uma maior compreensão sobre a qualidade de vida da população portuguesa em geral, das pessoas com afasia e dos seus familiares. Isto permitirá, no futuro, conhecer e ajudar, de modo mais eficaz, essas pessoas. Por tudo isto, a sua colaboração é muito importante.

Qualquer um dos procedimentos utilizados não causará qualquer prejuízo à sua saúde ou vida. Poderá recusar a sua colaboração, em qualquer momento, sem que daí advenha algum prejuízo.

A sua participação implica o preenchimento dos seguintes instrumentos: Versão abreviada da World Health Organization Quality of Life Scale (WHOQOL-Bref); Domínio 3 da WHOQOL-100; Center for Epidemiologic Depression Scale (CES-D); e Ficha de dados pessoais adicionais.

No início de cada instrumento, são apresentadas as instruções de preenchimento. Não há respostas certas ou erradas, o importante é a sua opinião. É fundamental que leia atentamente e responda a todas as questões.

A primeira página da WHOQOL-Bref será preenchida pela investigadora, pelo que deve ser deixada em branco. Comece, pois, o preenchimento deste instrumento na página onde são solicitados os dados pessoais. O preenchimento de todos os questionários demora cerca de 15 minutos. Todos os dados recolhidos são confidenciais.

Caso não saiba ou não consiga ler ou escrever os questionários poderão ser lidos e preenchidos com o auxílio de outra pessoa. Todas as respostas deverão ser registadas de acordo com a opinião do participante.

Em caso de dúvida, por favor, contacte a investigadora através do contacto electrónico: bp.afasia@gmail.com.

Agradecemos, desde já, a sua participação neste estudo. O seu contributo é muito importante!

Muito Obrigada!

Appendix G: Frenchay Activities Index (FAI)

Código de participante: PCA-_____
(A preencher pelo investigador)

Frenchay Activities Index (FAI) – Versão Portuguesa

Nome: _____ Data:_____

Coloque o valor correspondente à resposta no espaço apresentado a seguir a cada item.

Durante os últimos 3 meses, com que frequência realizou as seguintes atividades:	
1. Preparar as refeições principais _____ 2. Lavar a loiça após as refeições _____	0 = Nunca 1 = Menos de uma vez por semana 2 = 1-2 vezes por semana 3 = Na maioria dos dias
3. Lavar a roupa _____ 4. Trabalhos domésticos leves _____ 5. Trabalhos domésticos pesados _____ 6. Fazer compras perto de casa _____ 7. Eventos sociais _____ 8. Caminhar no exterior > 15 minutos _____ 9. Dedicar-se ativamente a um passatempo _____ 10. Conduzir um carro/andar de autocarro _____	0 = Nunca 1 = 1-2 vezes em 3 meses 2 = 3-12 vezes em 3 meses 3 = Pelo menos uma vez por semana

Durante os últimos 6 meses, com que frequência realizou as seguintes atividades:	
11. Excursões/passear de carro _____	0 = Nunca 1 = 1-2 vezes em 6 meses 2 = 3-12 vezes em 6 meses 3 = Pelo menos uma vez por semana
12. Jardinagem/cuidar do quintal/horta _____ 13. Reparações/manutenção da casa/carro _____	0 = Nunca 1 = Tarefas leves 2 = Tarefas moderadas 3 = Tarefas pesadas/Sempre que necessário
14. Ler livros _____	0 = Nenhum 1 = 1 em 6 meses 2 = Menos de 1 em 2 semanas 3 = Mais de 1 em 2 semanas
15. Trabalho remunerado _____	0 = Nenhum 1 = Até 10 horas/semana 2 = 10-30 horas/semana 3 = Mais de 30 horas/semana

TOTAL: _____

Instruções para a aplicação do Frenchay Activities Index:

O Objetivo é avaliar atividades que requerem alguma iniciativa por parte do paciente. É importante que se concentre na frequência real da atividade realizada no passado recente, não no seu desempenho no passado distante nem no seu potencial. Uma atividade apenas pode ser quantificada num item.

Informação específica para cada item:

1. Deve fazer parte substancial da organização, preparação e confeção de uma refeição principal. Não apenas refeições ligeiras (como sandes) ou aquecer comida já preparada.
2. Deve fazer tudo ou partilhar em partes iguais, por exemplo, lavar ou secar e arrumar. Não apenas enxaguar um objeto ocasionalmente.
3. Organização da roupa para lavar e secar seja com o uso de máquina de lavar, à mão ou na lavandaria. Partilha a tarefa em partes iguais, por exemplo, colocar/retirar a roupa da máquina, estender e dobrar.
4. Limpar o pó, polir, passar a ferro, arrumar pequenos objetos ou roupas de cama. Tudo o que incluir trabalho mais pesado é considerado no item 5.
5. Todos os trabalhos de casa mais pesados incluindo mudar camas, lavar o chão, janelas, aspirar, mover cadeiras, etc.
6. Ter um papel substancial na organização e compra de mercearia quer seja quantidades pequenas ou grandes. Deve ir até à loja realizar as compras e não apenas empurrar um carrinho de supermercado. Pode incluir levantamento da pensão ou ida aos correios.
7. Participar em encontros de associações, em atividades da igreja, ir ao cinema, ao teatro, tomar uma bebida/ir ao café, jantar fora com amigos, etc. Pode ser transportado para o local, desde que depois de chegar tenha um papel ativo. Inclui receber pessoas em casa, por convite do paciente, por exemplo, visitas de familiares ou amigos cujo propósito da visita não seja prestar cuidados.
8. Caminhar continuamente pelo menos 15 minutos (são permitidas pequenas pausas para recuperar o folego). Cerca de 1500 metros. Pode incluir caminhar enquanto faz compras desde que as caminhadas sejam longas o suficiente.
9. Requer alguma participação ativa e organização mental, por exemplo, plantar/semear ou cuidar de plantas de casa, fazer malha, pintar, jogar, fazer desporto (não apenas ver desporto na televisão). Podem ser atividades mentais como ler revistas temáticas, gerir investimentos na bolsa, ou ver montras.
10. Deve conduzir o carro (não ser apenas o passageiro), ou apanhar o autocarro/camioneta e viajar nele de forma independente.
11. Viagens de autocarro, comboio ou carro em lazer. Não incluir os “eventos sociais” habituais (por exemplo ir às compras ou ir ter com amigos que vivam perto). Deve envolver alguma organização e tomada de decisão por parte do paciente. Exclui viagens organizadas por instituições a não ser que o paciente possa optar por ir ou não. O aspeto principal é que viaje em lazer. Férias nos últimos 6 meses são divididas em dias por mês, por exemplo, 7 dias de férias corresponde a *1 a 2 dias por mês*.
12. Jardinagem/Cuidar do quintal/horta:
    a. Tarefas leves: arranca ervas daninhas ou varre os carreiros.
    b. Tarefas moderadas: arranca ervas daninhas, passa o ancinho ou faz a poda, etc., regularmente.
    c. Tarefas Pesadas/Sempre que necessário: todo o tipo de trabalho necessário, incluindo cavar a terra.

Reparações/manutenção da casa/carro:

d. Tarefas leves: faz pequenas reparações, substitui lâmpadas ou fichas.
e. Tarefas moderadas: faz a limpeza geral anual, pendura um quadro, faz a manutenção simples do carro.
f. Tarefas pesadas/Sempre que necessário: Pinta/decora, faz a maior parte das reparações e da manutenção da casa/carro.

13. Leitura completa de livros, não inclui revistas ou jornais. Podem ser áudio-livros.
14. Trabalho para o qual o paciente é pago, não inclui voluntariado. Deve ser calculado o tempo médio de trabalho ao longo de 6 meses. Tomando o período de 6 meses como referência, pode calcular-se o trabalho de 18h/semana durante um mês, o que perfaz 3h/semana. Deve pontuar-se este exemplo como *até 10 horas por semana*.

Appendix H: Barthel Index (BI)

Código de participante: PCA-_____
(A preencher pelo investigador)

BARTHEL INDEX (BI) – VERSÃO PORTUGUESA

	Com ajuda	*Independente*
1. Alimentação (se precisar de cortar os alimentos = ajuda)	5	10
2. Move-se da cadeira de rodas para a cama e o inverso (inclui sentar-se na cama)	5-10	15
3. Cuidados pessoais (lavar o rosto, pentear-se, barbear-se, escovar os dentes)	0	5
4. Senta-se e levanta-se da sanita (manuseia as roupas, limpa-se, lava-se, puxa o autoclismo)	5	10
5. Toma banho sozinho	0	5
6. Caminha em terreno plano (ou se não for capaz de caminhar, é capaz de impulsionar a cadeira de rodas) *pontuar apenas se não for capaz de caminhar	10 0*	15 5*
7. Sobe e desce escadas	5	10
8. Veste-se e despe-se (inclui atar atacadores e usar botões/fechos)	5	10
9. Continência intestinal	5	10
10. Continência urinária	5	10

Um paciente que pontue 100 é continente, alimenta-se sozinho, veste-se sozinho, levanta-se da cama e das cadeiras, toma banho sozinho, caminha pelo menos 200 metros e consegue subir e descer escadas. Isto não significa que seja capaz de viver sozinho: pode não ser capaz de cozinhar,

manter a casa e atender à porta, mas é capaz de ficar sozinho sem necessidade de prestação de cuidados.

Definição e discussão da pontuação

1. **Alimentação**
   10 = Independente. O paciente consegue comer uma refeição numa bandeja ou mesa quando alguém a coloca ao seu alcance. Ele pode usar um dispositivo auxiliar, se necessário, para cortar a comida, usar sal e pimenta, espalhar manteiga, etc. Isto deve ser realizado num tempo razoável.

   5 = Alguma ajuda é necessária (para cortar a comida, etc, tal como enumerado anteriormente).

2. **Move-se da cadeira de rodas para a cama e o inverso**
   15 = Independente em todas as fases desta atividade. O paciente consegue com segurança aproximar-se da cama na sua cadeira de rodas, bloquear os travões, levantar os apoios, mover-se com segurança para a cama, deitar-se, assumir a posição de sentado lateralmente na cama, mudar a posição da cadeira de rodas, se necessário, para fazer a transferência de volta em segurança.

   10 = Se for necessária uma ajuda mínima em alguma parte desta atividade ou se o paciente precisar de ser lembrado ou supervisionado, por questões de segurança, numa ou mais partes desta atividade.

   5 = O paciente consegue assumir a posição de sentado sem ajuda de uma segunda pessoa mas precisa de ser levantado da cama, ou a transferência é realizada com muita ajuda.

Cuidados pessoais

   5 = O paciente consegue lavar as mãos e rosto, pentear o cabelo, lavar os dentes, e barbear-se. Ele pode usar qualquer tipo de lâmina, mas deve colocar a lâmina ou ligar a máquina de barbear sem ajuda, assim como retirá-la da gaveta ou armário. As pacientes devem ser capazes de se maquilhar, se for habitual, mas não precisam de fazer tranças ou penteados.

3. **Senta-se e levanta-se da sanita**
   10 = O paciente é capaz de sentar-se e levantar-se da sanita, apertar e desapertar a roupa, evitar sujar as roupas, e usa o papel higiénico sem ajuda. Ele pode usar uma barra

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de apoio na parede ou outro objeto estável para suporte, se necessário. Se for necessário o uso de uma arrastadeira em vez da sanita, ele deve ser capaz de a posicionar na cadeira, esvaziá-la, e limpá-la.

5 = O paciente precisa de ajuda devido à perda de equilíbrio ou no manuseio das roupas ou no uso de papel higiénico.

4. Toma banho sozinho

5 = O paciente pode usar uma banheira, um chuveiro ou tomar um banho completo com esponja. Ele deve ser capaz de realizar todos os passos envolvidos em qualquer um dos métodos aplicados sem nenhuma outra pessoa estar presente.

5. Caminha em terreno plano

15 = O paciente consegue andar pelo menos 45 metros sem ajuda ou supervisão. Ele pode usar ortóteses ou próteses, assim como muletas, bengalas ou andarilho mas não um andarilho com rodas. Ele deve ser capaz de bloquear e desbloquear ortóteses, se usar, colocar-se de pé e sentar-se, alcançar e posicionar as ajudas técnicas necessárias para o seu uso e colocá-las de lado quando se senta (colocar ou tirar as ortóteses é quantificado no item ***8. Veste-se e despe-se***).

10 = O paciente precisa de ajuda ou supervisão em qualquer das atividades descritas no ponto anterior mas consegue andar pelo menos 45 metros com uma pequena ajuda.

6.a. Impulsiona a cadeira de rodas

5 = Se um paciente não pode caminhar mas pode impulsionar uma cadeira de rodas independentemente. Ele deve ser capaz de contornar esquinas, virar, manobrar a cadeira até uma mesa, cama, sanita, etc. Deve ser capaz de impulsionar uma cadeira pelo menos 45 metros. Não pontue este item se o paciente foi pontuado no item ***6. Caminha em terreno plano***.

6. Sobe e desce escadas

10 = O paciente é capaz de subir e descer um lance de escadas em segurança sem ajuda ou supervisão. Pode e deve usar corrimões, bengalas, canadianas ou muletas se necessário. Deve ser capaz de segurar nas bengalas, canadianas ou muletas enquanto sobe ou desce as escadas.

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5 = O paciente precisa da ajuda ou supervisão de alguém nas atividades referidas no ponto anterior.

7. **Veste-se e despe-se**

   10 = O paciente deve ser capaz de vestir, despir e apertar toda a roupa e atar os atacadores dos sapatos (a menos que seja necessário usar adaptações para isso). A atividade inclui colocar e remover e apertar ortóteses quando estas são prescritas. Roupas especiais como suspensórios, sapatos sem atacadores, vestidos que abrem à frente, podem ser usados se necessário.

   5 = O paciente precisa de ajuda para vestir, despir ou apertar/desapertar qualquer peça de roupa. Deve fazer pelo menos metade da tarefa sozinho. Deve concluir a tarefa num tempo razoável.

As mulheres não precisam de ser pontuadas na utilização de soutien ou cinta, a não ser que se trate de peças de roupa prescritas.

8. **Continência intestinal**

   10 = O paciente é capaz de controlar os intestinos e não ocorrem acidentes. Pode aplicar supositório ou um clister quando necessário (como no caso dos pacientes com lesão vertebro-medular com controlo intestinal).

   5 = O paciente precisa de ajuda na aplicação de supositório ou clister ou ocorrem acidentes ocasionais.

9. **Continência urinária**

   10 = O paciente é capaz de controlar a sua bexiga de dia e de noite. Pacientes com lesão vertebro-medular que usam um dispositivo externo (por exemplo, um dispositivo urinário) e um saco coletor devem manuseá-los independentemente, limpá-los e esvaziar o saco, e manter-se seco de dia e de noite.

   5 = O paciente tem acidentes ocasionais ou não aguenta esperar pela arrastadeira, não consegue chegar a tempo à casa de banho ou precisa de ajuda com o dispositivo externo.

A pontuação 0 é atribuída a todas as atividades referidas anteriormente quando o paciente não consegue preencher os critérios definidos anteriormente.

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Appendix I: Mini-mental State Modificado (MMSM)

Código de participante: PCA-_____
(A preencher pelo investigador)

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MINI MENTAL STATE MODIFICADO (MMSM)

1. ORIENTAÇÃO

"Vou fazer-lhe algumas perguntas. A maior parte delas são fáceis. Tente responder o melhor que for capaz" (dar 1 ponto por cada resposta correcta).

a. Em que ano estamos?	
b. Em que mês estamos?	
c. Em que dia do mês estamos?	
d. Em que estação do ano estamos?	
e. Em que dia da semana estamos?	
f. Em que país estamos?	
g. Em que distrito vive?	
h. Em que terra vive?	
i. Em que casa estamos? (Como se chama esta casa onde estamos?)	
j. Em que andar estamos?	
Total	

a. "Em que ano estamos?" Aponte na folha para a palavra "ano" e para as 6 opções escritas apresentadas.
b. "Em que mês estamos?" Aponte para as 6 opções de palavras apresentadas nas quais se encontra a palavra alvo.
c. "Sabe em que dia do mês estamos?" "É…" Diga ao paciente qual o mês em que estamos, mostre-lhe o mês escrito nas folhas anteriores (se necessário). "Sabe a data de hoje?" O mês correto e possíveis datas são apresentados (escreva 6 opções de dias numa folha à parte, sem pistas quanto ao dia da semana).
d. "Em que estação do ano estamos?" Aponte para as 4 opções de palavras ou de imagens/palavras.
e. "Em que dia da semana estamos?" Mostre as opções possíveis na folha disponibilizada.
f. "Em que país estamos?"Aponte para cada um dos 6 nomes de países.
g. "Em que distrito vive?" Apresente/escreva, numa folha à parte, 6 opções possíveis entre as quais se encontra o distrito onde a pessoa vive.
h. "Em que terra vive?" Apresente/escreva, numa folha à parte, 6 opções possíveis entre as quais se encontra a terra onde vive.
i. "Em que casa estamos? Que edifício é este?" Apresente/escreva, numa folha à parte, 6 opções possíveis entre as quais se encontra o nome do local onde estão.
j. "Em que andar estamos? Apresente/escreva, numa folha à parte, 6 opções possíveis entre as quais se encontra o andar onde estão.

k. RETENÇÃO DE IMAGENS

"**Olhe para estas imagens e procure lembrar-se delas**. Aponte para a palavra **LEMBRAR** e depois para cada imagem durante 3 segundos. Remova as imagens"

"Quais as imagens que acabou de ver?" Mostre o conjunto de imagens A (3 imagens anteriores + 15 imagens diferentes).

a. Pêra (1) _____
b. Gato (1) _____
c. Bola (1) _____

Se o paciente omitir um dos itens apresentados, mostre novamente as primeiras 3 imagens, num total de 2 vezes. Caso o indivíduo não consiga, dê continuidade à prova.

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l. ATENÇÃO

Apresente o calendário com os meses do ano e o "quadro de sequência" com os números. Com o "quadro de sequência" na frente do indivíduo, diga "**Ponha os meses por ordem, começando de trás para a frente**". Inicie com Dezembro e ponha os meses por ordem andando para trás no ano (aponte para os quadrados numerados indicando a ordem que se pretende que siga). Pode ser dada a pista inicial "**Qual o mês que vem antes de Dezembro?**". Entregue os cartões com os meses (os meses devem ser colocados na posição correta para que a pontuação seja atribuída).

a. Novembro (1) _____ c. Setembro (1) ____ e. Julho (1) _____
b. Outubro (1) _____ d. Agosto (1) _____

m. EVOCAÇÃO

"**Quais as três imagens que lhe pedi há pouco para se lembrar?**" Mostre novamente as 18 opções.

a. Pêra (1) _____ b. Gato (1) _____ c. Bola (1) _____

n. LINGUAGEM (1 ponto por cada resposta correcta)

a. Mostrar o relógio de pulso durante 10 segundos. "**Como se chama isto?"** ___
b. Mostrar o lápis durante 10 segundos. "**Como se chama isto?"** ____
c. Repetir a frase. **"O rato rói a rolha"** ___ (Todas as palavras devem estar na ordem certa. Caso existam erros morfológicos, considere a resposta correta).

d. "Vou dar-lhe uma folha de papel. Quando eu lha entregar, pegue nela com a sua mão direita, dobre-a ao meio e coloque-a no chão".
Se o paciente apresentar défices motores, coloque três folhas coloridas em cima da mesa (uma vermelha, uma amarela e uma verde) e substitua o a frase por**: "Pegue na folha vermelha, dobre-a ao meio e ponha-a no chão"**.
(Se for necessário use a prancha com a frase escrita)

Pega no papel com a mão direita/folha de papel vermelho (1) _____
Dobra a folha ao meio (1) _____
Coloca-a no chão (1) _____

e. "**Leia e faça o que diz neste cartão"**. (Mostrar o cartão com a frase **"Feche os olhos".** Se o sujeito for analfabeto o examinador deverá ler-lhe a frase.

Cumpre (1) _____

f. **"Escreva uma frase".** (Forneça uma folha e um lápis ou caneta para que o indivíduo possa escrever). A frase deverá ter sujeito, verbo e ter sentido para ser pontuada com um ponto. Erros gramaticais ou troca de letras não contam como erros. Se o sujeito for analfabeto não se realiza este item.

Frase (1) _____

g. **"Copie o desenho que lhe vou mostrar"**. Aponte para a imagem dos pentágonos em intersecção, para a palavra "Copiar" e para uma folha com espaço em branco para a cópia (os 10 ângulos devem estar presentes e 2 deles devem estar intersectados para pontuar 1 ponto. Tremor e erros de rotação não são valorizados).

TOTAL (Máximo de 30 pontos) _____

Appendix J: Communication Disability Profile (CDP)

Código de participante: PCA-_____
(A preencher pelo investigador)

The Communication Disability Profile (CDP) – Versão Portuguesa

Folha de Pontuação Sumária

Data:

Pergunta sobre a disposição	**Boa**				**Má**			
Domínios	**Pontuação em bruto (assinale com um círculo)**					**Totais por secção**	**Percentagens totais**	
Actividades	**Mau**				**Bom**			
1 Falar – pessoa mais próxima	4	3	2	1	0			
2 Falar – grupo	4	3	2	1	0			
3 Falar – estranho	4	3	2	1	0			
4 Falar – pressão	4	3	2	1	0			
Falar total						***/16***		
5 Comunicar – pessoa mais próxima	4	3	2	1	0			
6 Comunicar – grupo	4	3	2	1	0			
7 Comunicar – estranho	4	3	2	1	0			
8 Comunicar – pressão	4	3	2	1	0			
Comunicação total						***/16***		
9 Compreender – pessoa mais próxima	4	3	2	1	0			
10 Compreender – grupo	4	3	2	1	0			
11 Compreender – estranho	4	3	2	1	0			
12 Compreender – pressão	4	3	2	1	0			
Compreender total						***/16***		
13 Ler – palavra	4	3	2	1	0			
14 Ler – título	4	3	2	1	0			
15 Ler – notícia	4	3	2	1	0			
16 Ler – formal	4	3	2	1	0			
Ler total						***/16***		
17 Escrever – nome	4	3	2	1	0			
18 Escrever – lista	4	3	2	1	0			
19 Escrever – amigo	4	3	2	1	0			
20 Escrever – formal	4	3	2	1	0			
Escrever total						***/16***		
Actividades total:								
(sem comunicar)						***(- comunicar)***	***/64***	***%***
						ou		
(com comunicar)						***(+ comunicar)***	***/80***	***%***

Participação	**Mau**				**Bom**		
tem que							
21 Compras	4	3	2	1	0		
22 Dinheiro	4	3	2	1	0		
23 Saúde	4	3	2	1	0		
24 Transportes	4	3	2	1	0		
25 Trabalho	4	3	2	1	0		
26 Papelada	4	3	2	1	0		
27 Mais alguma coisa?							
Quer	4	3	2	1	0		
28 Passatempos	4	3	2	1	0		
29 Café	4	3	2	1	0		
30 Férias	4	3	2	1	0		
31 Sair	4	3	2	1	0		
32 Encontros com amigos	4	3	2	1	0		
33 Relacionamentos	4	3	2	1	0		
34 Mais alguma coisa?							
35 **Em casa**	4	3	2	1	0		
Participação total						***/52***	***%***

.

Influências externas

Facilitadores

36 Pessoas

37 Dão-lhe atenção	Dizer às pessoas	Mais tempo
Imagens	Escrever as coisas	Ajuda de alguém
Áudio-livros	Dicionário de palavras	Computador
Outras coisas?		

Barreiras

36 Pessoas

38 Barreira de vidro	Filas	Sob pressão
Perturbado	Sua mão	Cansado
Muita coisa	Telefone	2 pessoas a falar ao mesmo tempo
Falam depressa	Olham noutra direcção	Barulho e confusão
Interrompem-no	Mais longe	Mais alguma coisa?

Emoções		**Mau**				**Bom**
39 Zangado		4	3	2	1	0
40 Frustrado		4	3	2	1	0
41 * Determinado	INVERTIDA	(0	1	2	3	4)
42 Infeliz		4	3	2	1	0
43 Preocupado		4	3	2	1	0
44 * Satisfeito	INVERTIDA	(0	1	2	3	4)
45 Pouco confiante		4	3	2	1	0
46 Com falta de controlo		4	3	2	1	0
47 * Capaz	INVERTIDA	(0	1	2	3	4)
48 Sozinho		4	3	2	1	0
49 Envergonhado		4	3	2	1	0
50 * Valorizado	INVERTIDA	(0	1	2	3	4)
51 Futuro		4	3	2	1	0
52 Actualmente		4	3	2	1	0
53 Gosta						
54 Mais alguma coisa?						
55 Alguma coisa sobre a vida?						

Emoções total ***/56*** ***%***

* questões enunciadas positivamente – requerendo que a pontuação seja invertida.

Continue na página seguinte

Totais Globais					
Actividades		**Participação**		**Emoções**	
/64	**%**	**/52**	**%**	**/56**	**%**
ou					
/80	**%**				

Pessoas chave:

Questões chave:

Acção possível:

Administrado por:

Appendix K: Lisbon Aphasia Assessment Battery (LAAB)

Código de participante: PCA-_____
(A preencher pelo investigador)

Bateria de Avaliação de Afasia de Lisboa

Data da avaliação	_____/_____/_____

Dados gerais:

Por favor, preencha cada um dos espaços com uma cruz (x) ou com a informação solicitada acerca da pessoa com afasia em estudo.

Etiologia da afasia	
Data de instalação	_____/_____/_____
Quanto tempo em esteve internado?	
Há quanto tempo teve alta do internamento?	

Lesões cerebrais anteriores	Sim	
	Não	

Comprometimento motor actual	Sim		Qual? _____
	Não		

Provas Nucleares da Bateria de Avaliação de Afasia de Lisboa:

Por favor, preencha cada um dos espaços com uma cruz (x) ou coloque o número a que corresponde o valor da resposta.

Avaliação do discurso

Coloque ma cruz (x) no espaço que corresponde ao tipo de discurso que a pessoa apresenta.

Não-Fluente	0 – Ausência de discurso	
	1 – Estereotipo	
	2 – Estereotipo com prosódia adequada	
	3 – Palavras ocasionalmente correctas	
	4 – Frases telegráficas	
	5 – Defeitos de articulação e/ou eventuais parafasias	
Fluente	0 – Jargonofasia	
	1 – Predomínio de parafasias	
	2 – Predomínio de circunlóquio	
	3 - Predomínio de pausas anómicas	
	4 – Algumas pausas anómicas e/ou ocasionais parafasias	
	5 – Fluência normal sem pausas ou parafasias	

Nomeação de objectos

Coloque 1 ou 0 (zero) de acordo com as respostas dadas de forma correcta ou incorrecta, respectivamente.

Série A	
Lápis	
Escova	
Garfo	
Alfinete	
Tesoura	
Moeda	
Fósforo	
Canivete	

Série B	
Espelho	
Caneta	
Colher	
Nota	
Frasco	
Selo	
Campainha	
Carteira de fósforos	

Total	_____/_____

Compreensão de ordens simples

Coloque 1, 0,5 ou 0 (zero) de acordo com as respostas dadas de forma correcta na primeira tentativa, na segunda tentativa ou de forma incorrecta, respectivamente.

Dirigidas ao corpo	
Feche os olhos	
Abra a boca	
Deite a língua de fora	
Ponha a mão na orelha	

Dirigidas a objectos	
Agarre no lápis	
Pegue na moeda e no garfo	
Ponha o fósforo em cima de tesoura	
Ponha o alfinete ao lado da escova	

Total	_____/8

Repetição de palavras

Coloque 1 ou 0 (zero) de acordo com as respostas dadas de forma correcta ou incorrecta, respectivamente.

Lápis	
Garfo	
Selo	
Nota	
Botão	
Pente	
Chave	
Faca	
Roda	
Vela	

Fósforo	
Tesoura	
Espelho	
Borracha	
Cigarro	
Janela	
Caneta	
Bilhete	
Árvore	
Cinzento	

Canivete	
Automóvel	
Lavatório	
Margarina	
Camisola	
Alfinete	
Descoberta	
Ratazana	
Sapateiro	
Laranjeira	

Total	_____/30

Sumário dos dados da avaliação:

Diagnóstico	Afasia Anómica	
	Afasia Condução	
	Afasia Broca	
	Afasia Wernicke	
	Afasia Global	
	Afasia Transcortical Motora	
	Afasia Transcortical Sensorial	
	Afasia Transcortical Mista	

Quociente de afasia	_____

Appendix L: Carers' Assessment of Managing Index

Código de participante: C-_____
(A preencher pelo investigador)

Índice para avaliação das maneiras como o prestador de cuidados enfrenta as dificuldades

(CAMI – Carers' Assessment of Managing Index)

[Elaborado por Nolan, Grant e Keady (1998) e validado para a língua portuguesa por Brito (2002)]

O CAMI é uma lista de 30 afirmações, feitas por pessoas que prestam cuidados, acerca da forma como habitualmente enfrentam as suas dificuldades. Leia atentamente cada uma das afirmações e indique de que modo se aplicam ao seu caso, colocando o sinal **X** no espaço que melhor corresponder à sua opinião.

	Uma das maneiras de enfrentar as dificuldades que tenho, ao cuidar desta pessoa, é:	**Não procedo desta forma**	**Faço assim e acho que:**		
			Não dá resultado	**Dá algum resultado**	**Dá bastante bom resultado**
1	Estabelecer um programa regular de tarefas, e procurar cumpri-lo				
2	Descarregar a tensão, falando alto, gritando, ou coisa semelhante				
3	Falar dos meus problemas com alguém em quem confio				
4	Reservar algum tempo livre para mim próprio				
5	Planear com antecedência e assim estar preparado para as coisas que possam acontecer				
6	Ver o lado cómico da situação				
7	Pensar que há sempre quem esteja pior do que eu				
8	Cerrar os dentes e continuar				
9	Recordar todos os bons momentos que passei com a pessoa de quem cuido				
10	Procurar obter toda a informação possível acerca do problema				
11	Pensar que a pessoa de quem cuido não tem culpa da situação em que está				
12	Viver um dia de cada vez				
13	Conseguir que a família me dê toda a ajuda prática que puder				
14	Manter a pessoa de quem cuido tão activa quanto possível				
15	Modificar as condições da casa de modo a facilitar as coisas o mais possível				
16	Pensar que a situação está agora melhor do que antes				

17	Obter toda a ajuda possível dos serviços de saúde e dos serviços sociais				
18	Pensar no problema e encontrar uma forma de lhe dar solução				
19	Chorar um bocado				
20	Aceitar a situação tal como ela é				
21	Arranjar maneira de não pensar nas coisas, lendo, vendo televisão ou algo semelhante				
22	Fazer como se o problema não existisse e esperar que ele passe				
23	Tomar medidas para evitar que os problemas surjam				
24	Agarrar-me a fortes crenças pessoais ou religiosas				
25	Acreditar em mim próprio e na minha capacidade para lidar com a situação				
26	Esquecer os problemas por momentos, deixando divagar o pensamento				
27	Manter dominados os meus sentimentos e emoções				
28	Tentar animar-me comendo, bebendo um copo, fumando ou outra coisa do género				
29	Confiar na minha própria experiência e na competência que tenho adquirido				
30	Experimentar várias soluções até encontrar uma que resulte				
31	Estabelecer uma ordem de prioridades e concentrar-me nas coisas mais importantes				
32	Procurar ver o que há de positivo em cada situação				
33	Ser firme com a pessoa de quem cuido e fazer-lhe ver o que espero dela				
34	Pensar que ninguém tem culpa da situação				
35	Descarregar o excesso de energia e sentimentos, andando, nadando ou fazendo outro exercício físico				
36	Reunir regularmente com um grupo de pessoas com problemas semelhantes				
37	Usar técnicas de relaxamento, meditação ou outras				
38	Dedicar-me a coisas que me interessam, para além de cuidar da pessoa				

Se tem outras maneiras de enfrentar os problemas, por favor indique-as a seguir e assinale, como fez atrás, em que medida lhe parece que dão resultado.

		Faço assim e acho que:		
Uma das maneiras de enfrentar as dificuldades que tenho, ao cuidar desta pessoa, é:		**Não dá resultado**	**Dá algum resultado**	**Dá bastante bom resultado**

Appendix M: Sociodemographic datasheet for PWA

Código de participante: PCA-_____
(A preencher pelo investigador)

Dados Adicionais

Por favor, preencha cada um dos espaços com uma cruz (x) ou com a informação solicitada.

1.	**Ocupação**	Empregado	
		Desempregado	
		Reformado	
		Voluntário	

2.	**Baixa médica**	Sim	
		Não	

3.	**Habita com**	Sozinho	
		Cônjuge	
		Filho(s)	
		Pai	
		Mãe	
		Irmão(s)	
		Sogro	
		Sogra	
		Nora	
		Genro	
		Outro(s)	

Com quantos filhos vive? _____

Com quantos irmãos vive? _____

Quais? _____
Quantas são as "outras" pessoas que vivem consigo? _____

4.	**Frequência de terapia da fala**	Presente	
		Passado	
		Não frequentou	

Há quanto tempo frequenta? _____ meses

Durante quanto tempo frequentou? _____ meses
Há quanto tempo deixou de frequentar? _____ meses

5.	**Pense naquilo que mais influencia a sua qualidade de vida**

5.1.	**Escreva uma lista desses aspetos/coisas**

5.2.	**Quais os <u>3 aspetos/coisas que mais influenciam</u> a sua qualidade de vida?**

5.3.	**Quais as áreas/aspetos da sua vida que mais foram <u>influenciados pela existência da afasia</u>?**	

6.	Considere a **<u>pessoa com maior rendimento no seu agregado familiar</u>.** Assinale o grupo a que essa pessoa pertence.

6.1.	**Grupo ocupacional***	Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 6 ou mais trabalhadores	
		Quadro superior (responsável por 6 ou mais trabalhadores)	
		Quadro superior (responsável por 5 ou menos trabalhadores)	
		Profissão liberal ou similar	
		Quadro médio (responsável por 6 ou mais trabalhadores)	
		Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 5 ou menos trabalhadores	
		Profissão técnica, científica e artística por conta de outrem	
		Quadro médio (responsável por 5 ou menos trabalhadores)	
		Empregado de escritório	
		Estudante, doméstica, inactivo	
		Empregado trabalhando sem ser em escritório	
		Trabalhador manual ou similar por conta própria	
		Desempregado	
		Trabalhador manual por conta de outrem	

6.2.	**Escolaridade**	Não sabe ler nem escrever	
		Sabe ler ou escrever sem possuir diploma	
		1º Ciclo do Ensino Básico (antiga 4ª classe)	
		2º Ciclo do Ensino Básico (antigo 6º ano)	
		3º Ciclo do Ensino Básico (antigo 9º ano)	
		11º-12º Anos de escolaridade	
		Bacharelato ou frequência de curso superior	
		Licenciatura ou mais	

*****Caso a pessoa tenha várias atividades, considere a atividade principal de onde resultam os rendimentos. Caso a pessoa seja reformada, considere a atividade que exercia antes de se reformar.

Appendix N: Sociodemographic datasheet for the caregivers

Dados Adicionais

Por favor, preencha cada um dos espaços com uma cruz (x) ou com a informação solicitada.

1.	**Ocupação**	Empregado	
		Desempregado	
		Reformado	
		Voluntário	

2.	**Baixa Médica**	Sim	
		Não	

3.	**Habita com**	Sozinho		
		Cônjuge		
		Filho(s)		Com quantos filhos vive? _____
		Pai		
		Mãe		
		Irmão(ãos)		Com quantos irmãos vive? _____
		Sogro		
		Sogra		
		Nora		
		Genro		
		Outro(s)		Quais? _____ Quantas são as "outras" pessoas que vivem consigo? _____

4.	**Em média, quantas horas passa, por dia, com a pessoa com afasia?**	_____ horas por dia

5.	**Pense naquilo que mais influencia a sua qualidade de vida**

5.1.	**Escreva uma lista desses aspetos/coisas.**

5.2.	**Quais os <u>3 aspetos/coisas que mais influenciam</u> a sua qualidade de vida?**

5.3.	**Quais as áreas/aspetos da sua vida que mais foram <u>influenciados pela existência da afasia</u>?**

6.	Considere a **pessoa com maior rendimento no seu agregado familiar**. Assinale o grupo a que essa pessoa pertence.

6.1.	Grupo ocupacional*		
		Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 6 ou mais trabalhadores	
		Quadro superior (responsável por 6 ou mais trabalhadores)	
		Quadro superior (responsável por 5 ou menos trabalhadores)	
		Profissão liberal ou similar	
		Quadro médio (responsável por 6 ou mais trabalhadores)	
		Patrão/proprietário (agricultura, comércio, indústria, serviços) de empresa/loja/exploração com 5 ou menos trabalhadores	
		Profissão técnica, científica e artística por conta de outrem	
		Quadro médio (responsável por 5 ou menos trabalhadores)	
		Empregado de escritório	
		Estudante, doméstica, inactivo	
		Empregado trabalhando sem ser em escritório	
		Trabalhador manual ou similar por conta própria	
		Desempregado	
		Trabalhador manual por conta de outrem	

6.2.	Escolaridade		
		Não sabe ler nem escrever	
		Sabe ler ou escrever sem possuir diploma	
		1º Ciclo do Ensino Básico (antiga 4ª classe)	
		2º Ciclo do Ensino Básico (antigo 6º ano)	
		3º Ciclo do Ensino Básico (antigo 9º ano)	
		11º-12º Anos de escolaridade	
		Bacharelato ou frequência de curso superior	
		Licenciatura ou mais	

* Caso a pessoa considerada tenha várias atividades, considere a atividade principal de onde resultam os rendimentos. Caso a pessoa seja reformada, considere a atividade que exercia antes de se reformar.

Muito Obrigada pela sua colaboração!

Appendix O: Assessment of the usability of WHOQOL-Bref with PWA

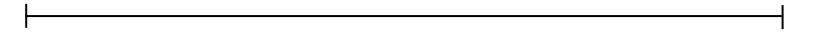
Código de participante: PCA-_____
(A preencher pelo investigador)

Avaliação da utilização do WHOQOL-Bref

Considerando a aplicação do WHOQOL-Bref às pessoas com afasia (PCA), por favor, responda às seguintes questões utilizando a escala de disponibilizada. Coloque uma cruz (x) no local que melhor representa a sua resposta.

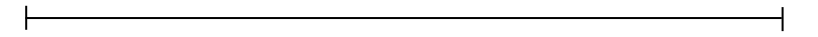
De acordo com a sua opinião, classifique:

1. A facilidade com que a PCA entendeu as questões do WHOQOL-Bref



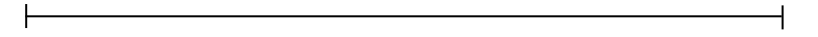
Fácil — Difícil

2. A facilidade com que a PCA indicou as respostas



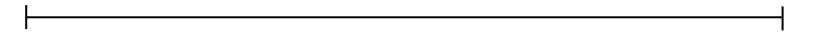
Fácil — Difícil

3. A ajuda que a PCA precisou



Nenhuma — Muitíssima

4. O nível de facilidade com que utilizou o WHOQOL-Bref com a PCA, em geral



Fácil — Difícil

Indique quanto tempo demorou a aplicação do WHOQOL-Bref (em minutos): _____

Appendix P: Ethical approval from institutions to collect data from PWA and their caregivers

Centro Hospitalar de
Trás-os-Montes e Alto Douro, EPE

Exm°(a). Senhor(a):
Dra. Brígida Patrício
Rua da Praia, nº 103 - 1º DIº
4485-354 LABRUGE

ASSUNTO: **Autorização para Realização de Investigação - "Impacto das Alterações da Comunicação na Qualidade de Vida das Pessoas com Afasia e na dos seus Familiares"**

V/ REFERÊNCIA

Em resposta ao pedido de V. Exa., de 03.05.2012, sobre o assunto em referência, cumpre-me informar que o Conselho de Administração do CHTMAD deliberou, em reunião de 08 de Maio de 2012, autorizar o solicitado.

Mais informo que, para efeitos de articulação, deverá entrar em contacto (276-300914) com a Vogal do Conselho de Administração, na Unidade Hospitalar de Chaves, Sra. Dra. Emília Carneiro.

Com os melhores cumprimentos,

O PRESIDENTE DO CONSELHO DE ADMINISTRAÇÃO

Dr. Carlos Vaz

Vila Real, 09.05.2012

Doc nº. 270/2012 - C.A.

Hospital Espírito Santo E.P.E.

27/07/12 09:51

Exmia. Senhora
Dra. Brigida Patrício
Rua da Praia nº 103 1º Dto
4485-354 Labruge

Sua Referência	Sua Comunicação	Nossa Referência	Data
Carta	01.08.2012		

Assunto: **Pedido de autorização para realização de investigação _ " Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares".**

Em referência ao assunto supracitado, informa-se a Vexa que o seu pedido foi deferido.

Com os melhores cumprimentos,

DIRECTOR CLINICO

(Manuel Canyaibó)

MLAP

HOSPITAL DE FARO EPE
Ministério da Saúde

Exma. Senhora
Ana Brigida Francisco Patricio
Rua da Praia nº103 1ºDto
4485-354 Labruge

Comissão de Ética para a Saúde

Sua Comunicação Ref.ª NA/ME/125/10 | N/ ref.ª | Data

Assunto: Estudo de investigação" Impacto das Alterações da Comunicação na Qualidade de vida das Pessoas com Afasia e na dos seus Familiares"

De acordo com o vosso pedido cumpre-me informar Vª. Exª. que o mesmo mereceu o seguinte Despacho do Conselho de Administração

"Autorizado"

Em anexo envio cópia do respectivo despacho.

Com os melhores cumprimentos,

Faro, 20 de Junho de 2012

O secretariado da Comissão de Ética
para a Saúde do Hospital Distrital de Faro EPE

centro hospitalar
do Porto

Hospital Santo António | Hospital Maria Pia Maternidade Júlio Dinis | Hospital Joaquim Urbano

Largo Prof. Abel Salazar
4099-001 PORTO
www.hgsa.pt

Exma. Sr.ª
Ana Brigida Patricio
R. da Praia, 103 – 1.º Dt.
4485-354 Labruge

ASSUNTO: Trabalho Académico Doutoramento - **"Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares" - N/ REF.ª 301/12(210-DEFI/244-CES)**

O Conselho de Administração do CHP **autoriza** a realização do estudo de investigação acima mencionado nesta Instituição, no Serviço de Medicina Física e Reabilitação, sendo Investigador Principal a Terapeuta da Ana Brigida Patrício.

O estudo de investigação foi previamente analisado pela Comissão de Ética para a Saúde e pelo Gabinete Coordenador de Investigação do Departamento de Ensino, Formação e Investigação do CHP, bem como pela Direcção Clínica, tendo obtido Parecer Favorável.

Cumprimentos,

CONSELHO DE ADMINISTRAÇÃO
14/12/2012
Dr. SOMARI ALLEGRO — Presidente
Dr.ª ÉLIA GOMES — Vogal Executiva
Dr. PAULO BARBOSA — Vogal Executivo
Dr. PORTO GOMES — Vogal Executivo
Enf.º EDUARDO ALVES — Vogal Executivo

* Em todas as eventuais comunicações posteriores sobre este estudo é indispensável indicar a nossa ref.ª.

POLITÉCNICO DO PORTO

Ana Patrício <abp@eu.ipp.pt>

Autorização para recolha de dados

Olivia Pestana <Olivia.Pestana@ulsm.min-saude.pt> 15 de Junho de 2012 09:10
Para "brigidapatricio@gmail.com" <brigidapatricio@gmail.com>

Exma.. Senhora
Dra. Brígida Patrício,

Em resposta à solicitação de v/ Exa. relativamente ao pedido de autorização para a realização do estudo intitulado "Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares/cuidadores", venho informar que o pedido foi autorizado em reunião do Conselho de Administração de de 12 de Junho de 2012, após parecer favorável da Comissão de Ética.

Mais informo que deve ser dado conhecimento ao SFGIC da produção científica sob a forma de artigos, conferências, livros, teses, relatórios de livre acesso, etc., devendo ser depositado um exemplar na Biblioteca, sempre que possível em suporte electrónico.

Com os melhores cumprimentos
Olívia Pestana
Directora do Serviço de Estudos e de Gestão da Informação Científica

Unidade Local de Saúde de Matosinhos, E.P.E.
Rua Dr. Eduardo Torres, 4464-513 Senhora da Hora | Portugal
Telefone: + 351 229 391 233 | Fax: + 351 229 391 231
Extensão: 1233
E-mail: olivia.pestana@ulsm.min-saude.pt
Web site: http://www.ulsm.min-saude.pt/

Appendix Q: Cover letter for speech and language therapists

Caro(a) Colega,

No âmbito do estudo de doutoramento "Impacto das alterações de comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares" realizado por Brígida Patrício na Universidade de Aveiro com orientação do Professor Doutor Luís Jesus e pela Professora Doutora Madeline Cruice, em que aceitou colaborar, segue, dentro deste envelope, todo o material necessário para a recolha de dados junto de pessoas com afasia e de seus familiares/cuidadores.

Dentro deste envelope encontrará:

1) Uma folha de informações e procedimentos gerais;
2) Uma folha com instruções gerais para aplicação dos instrumentos;
3) Envelopes 1 (para as pessoas com afasia);
4) Envelopes 2 (para os familiares/cuidadores das pessoas com afasia);
5) Envelope para consentimentos informados;
6) Materiais de apoio para aplicação do Mini-Mental State Modificado, versão portuguesa (MMSM), nomeadamente: folha com lista de material necessário; pranchas de apoio; 2 folhas/calendários com os meses do ano por extenso e em números; 3 folhas coloridas; 1 folha branca; 6 cartões com meses do ano e 1 cartão com uma frase;
7) Materiais de apoio para aplicação do Communication Disability Profile, versão portuguesa 1 (CDP), nomeadamente: folha com lista de material necessário e esclarecimentos gerais; escalas de resposta e imagens de suporte;

Para que um indivíduo com afasia e seu familiar/cuidador possa fazer parte deste estudo deverá respeitar os critérios de inclusão definidos. Para consultar esta e outras informações importantes consulte a folha "Informações e procedimentos gerais" que segue neste envelope.

Para qualquer esclarecimento adicional, por favor, entre em contacto comigo para o endereço eletrónico brigidapatricio@gmail.com ou através do número 916 865 892.

Certa de que juntos poderemos contribuir para uma melhor prestação de serviços à pessoa com afasia e aos seus familiares/cuidadores, agradeço pela colaboração que aceitou prestar neste estudo.

Disponível para qualquer esclarecimento que julgue conveniente.

Com os melhores cumprimentos

Appendix R: Procedures information

Informações e procedimentos gerais

Por cada par de participantes serão usados 2 envelopes distintos com a seguinte informação:

Envelope 1: Informações para a pessoa com afasia (PCA) e folhas de registo de instrumentos que serão administrados pelo terapeuta da fala (TF) à PCA.

Envelope 2: Informações e questionários dirigidos ao familiar/cuidador (C) da PCA.

Dentro do envelope 1 constam:	Dentro do envelope 2 constam:
- Folha de esclarecimento do estudo para a PCA - Consentimento informado para a PCA - WHOQOL-Bref - Domínio das relações sociais da WHOQOL-100 - CES-D - Ficha de dados adicionais - Ficha de preenchimento da BAAL - Frenchay Activities Index - Índice de Barthel - Ficha de preenchimento do MMSM - Ficha de preenchimento do CDP (as pranchas de apoio do MMSM e CDP estão fora do envelope) - Avaliação da utilização da WHOQOL-Bref (a ser respondido pelo TF)	- Ficha de apresentação do estudo - Consentimento informado - WHOQOL-Bref - Domínio das relações sociais da WHOQOL-100 - CES-D - Carers' Assessment of Managing Index - Ficha de dados adicionais

Pede-se ao TF que entregue o envelope 2 ao cuidador da PCA e que o recolha quando este estiver preenchido.

O TF deverá ler a ficha de esclarecimento do estudo dirigida à PCA em voz alta, assim como o consentimento informado. Todos os instrumentos do envelope 1 dirigidos à PCA são aplicados com a ajuda do TF que deverá lê-los em voz alta e registar as respostas de acordo com a opinião da PCA. O questionário de avaliação da utilização da WHOQOL-Bref é para ser respondido apenas pelo TF. O familiar/cuidador da PCA deverá responder a todos os instrumentos incluídos no envelope 2. Caso o cuidador necessite de ajuda deverá solicitá-la ao TF.

Os materiais de apoio para aplicação de alguns dos instrumentos que o TF irá usar seguem fora do envelope 1 para que possam ser usados para mais do que um participante.

Se necessário, as folhas de preenchimento de todos os instrumentos contidos nos envelopes 1 e 2 podem ser fotocopiadas para que mais indivíduos possam participar no estudo. Caso isto aconteça, por favor, coloque os instrumentos/questionários dentro dos envelopes vazios e codifique-os seguindo o mesmo procedimento dos envelopes enviados. Se desejar, entre em contacto com o investigador para que seja enviado material para mais participantes.

Os documentos do envelope 1, à excepção do consentimento informado, devem ser recolocados dentro do mesmo envelope após o devido preenchimento por parte do TF.

Os questionários do envelope 2 poderão ser preenchidos no local que o cuidador considerar mais conveniente. Uma vez preenchidos, esses questionários deverão ser devolvidos ao TF, no respectivo envelope fechado.

Todos os consentimentos informados (das PCA e dos C) deverão ser colocados, pelo TF, no envelope para o efeito codificado como "consentimentos informados".

Os envelopes de cada par de participantes deverão ser codificados com o mesmo número, antecedidos do código do local de recolha de dados.

Considerando o exemplo da pessoa com afasia número 1 e do seu familiar/cuidador, também número 1:

Código do envelope 1: PCA-IniciaisInstituição-NumeroParticipante, p.e., PCA-HJD-1

Código do envelope 2: C-IniciaisInstituição-NumeroParticipante, p.e., C-HJD-1

Para que um indivíduo com afasia e seu familiar/cuidador possa fazer parte deste estudo deverá respeitar os seguintes critérios de inclusão:

Pessoas com afasia:

- Ter idade igual ou superior a 20 anos;
- Ter pelo menos 3 meses após o acidente vascular cerebral (AVC);
- Ser falante nativo do português europeu;
- Ter nacionalidade portuguesa e viver em Portugal;
- A viver em casa própria ou em casa de familiares/cuidadores;
- Diagnóstico de afasia baseado nos resultados da Bateria de Avaliação de Afasia de Lisboa (BAAL). Os indivíduos deverão ter resultados iguais os superiores a 7 na prova de compreensão de ordens simples e/ou boas competências de compreensão de material escrito;
- Sem alterações cognitivas ou auditivas diagnosticadas ou por diagnosticar que afetem a performance comunicativa.

Familiares/cuidadores:

- Ser cuidador de uma pessoa com afasia;
- Estar com a pessoa com afasia, em média, pelo menos 8h/dia;
- Ser falante nativo do português europeu;
- Ter nacionalidade portuguesa e a residir em Portugal;
- Sem perturbações cognitivas ou outras que afetem a linguagem e/ou comunicação.

Appendix S: General instructions for instruments appliance

Guia de instruções gerais para a aplicação dos instrumentos

Relativamente a cada um dos seguintes instrumentos:

- Índice de Barthel (BI);

- Frenchay Activities Index (FAI);

- World Health Organization Quality of Life Scale (WHOQOL-Bref e domínio das relações sociais da WHOQOL-100);

- Center for Epidemiologic Studies Depression Scale (CES-D);

- Ficha de dados adicionais;

Siga as instruções de aplicação específicas presentes em cada instrumento.

Leia todas as questões e opções de resposta em voz alta. Registe as respostas de acordo com a resposta do indivíduo.

É fundamental que o indivíduo entenda o que lhe está a ser perguntado e que o TF entenda o que está a ser respondido. Se houver dificuldades a estes níveis, use comunicação total para que o indivíduo entenda a questão e/ou para que o TF entenda a resposta. Certifique-se, no entanto, de que dá **apenas a ajuda necessária** para que o processo comunicativo seja eficaz.

Seguem-se alguns exemplos do que poderá ser feito.

Caso o indivíduo apenas precise que faça leitura em voz alta da informação/opções de resposta, por favor, leia a informação/opções de respostas em voz alta, sem adicionar mais informação.

Se necessário, repita a informação/opções de respostas. Neste caso, para além de registar a resposta do indivíduo, assinale a questão com um R representando que a questão necessitou de ser repetida. Se uma ajuda diferente for necessária, por favor, assinale a questão com um A.

Reformule as frases apenas se necessário. Certifique-se de que o conteúdo se mantém o mesmo na frase reformulada.

Caso o indivíduo necessite de ouvir e ver a informação verbal, leia e mostre a informação/opções de resposta presentes no instrumento. Caso o indivíduo não consiga ler o tamanho de letra que é apresentado no instrumento, reescreva a informação numa folha à parte. Se apenas for necessário escrever as palavras-chave, escreva apenas as palavras-chave.

Se o indivíduo tiver dificuldades de expressão verbal oral, ele poderá apontar ou escrever a resposta. Se necessário, escreva as opções de resposta numa folha à parte para que o indivíduo aponte.

O indivíduo poderá também responder às questões usando comunicação não-verbal.

Use exemplos apenas quando os instrumentos sugerirem a sua utilização. Nesse caso, dê apenas os exemplos contemplados no instrumento.

Caso os instrumentos não sugiram a utilização de exemplos, não os use.

Deixe que o indivíduo responda por si próprio, não induza qualquer tipo de resposta.

Appendix T: Study information for PWA

Apresentação do estudo

Pessoas com afasia

Estudo:

Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares

Investigador:

Ana Brígida Francisco Patrício

Doutoramento em Ciências e Tecnologias da Saúde, Universidade de Aveiro

Orientadores:

Professor Doutor Luís Miguel Teixeira de Jesus, Universidade de Aveiro

Professora Doutora Madeline Cruice, City University, Londres

O presente estudo pretende recolher dados que permitam conhecer melhor as necessidades das pessoas com afasia e dos seus familiares, para que possam ser ajudados de forma mais eficaz. A sua finalidade é científica e académica.

Os dados são recolhidos através de uma ficha de caracterização e de questionários que avaliam:

- Qualidade de vida (WHOQOL-Bref e domínio 4 da WHOQOL-100);
- Humor (Center for Epidemiological Studies Depression Scale);
- Participação em atividades do dia-a-dia (Frenchay Activities Index e Índice de Barthel);
- Cognição (Language Modified Mini-Mental State Examination);
- Linguagem (Bateria de Avaliação de Afasia de Lisboa);
- Comunicação funcional (Communication Disability Profile).

Todos os questionários serão preenchidos com a ajuda do terapeuta da fala.

Para participar deverá assinar o consentimento informado.

Não há respostas certas nem erradas, o importante é a sua opinião. Responda a todas as questões.

Garantimos o anonimato e confidencialidade dos dados recolhidos.

A sua participação não causará qualquer prejuízo à sua saúde ou vida.

Poderá recusar a sua colaboração, em qualquer momento, sem qualquer prejuízo.

Se tiver dúvidas, pergunte ao Terapeuta da Fala que está a colaborar no estudo, ou contacte a investigadora através de bp.afasia@gmail.com ou do número de telefone 916 865 892.

Muito obrigada por participar. O seu contributo é muito importante!

Appendix U: Study information for the caregivers

Apresentação do estudo

Familiares/cuidadores de pessoas com afasia

Estudo:

Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares

Investigador:

Ana Brígida Francisco Patrício

Doutoramento em Ciências e Tecnologias da Saúde, Universidade de Aveiro

Orientadores:

Professor Doutor Luís Miguel Teixeira de Jesus, Universidade de Aveiro

Professora Doutora Madeline Cruice, City University, Londres

O presente estudo pretende recolher dados que permitam conhecer melhor as necessidades das pessoas com afasia e dos seus familiares, para que possam ser ajudados de forma mais eficaz. A sua finalidade é científica e académica.

Se é familiar ou cuidador de uma pessoa com afasia, por favor, participe.

Os dados são recolhidos através de uma ficha de caracterização e de questionários que avaliam:

- Qualidade de vida (WHOQOL-Bref e domínio 4 da WHOQOL-100);
- Humor (Center for Epidemiological Studies Depression Scale)
- Forma como lida com a situação de viver/cuidar de uma pessoa com afasia (Carers' Assessment of Managing Index)

Todos os questionários são preenchidos por si. Se necessitar de ajuda, poderá solicitá-la ao terapeuta da fala.

Para participar deverá assinar o consentimento informado.

Não há respostas certas nem erradas, o importante é a sua opinião. Responda a todas as questões.

Garantimos o anonimato e confidencialidade dos dados recolhidos.

A sua participação não causará qualquer prejuízo à sua saúde ou vida.

Poderá recusar a sua colaboração, em qualquer momento, sem qualquer prejuízo.

Se tiver dúvidas, pergunte ao Terapeuta da Fala que está a colaborar no estudo, ou contacte a investigadora através de bp.afasia@gmail.com ou do número de telefone 916 865 892.

Muito obrigada por participar. O seu contributo é muito importante!

Appendix V: Informed consent for PWA

DECLARAÇÃO DE CONSENTIMENTO

Considerando a "Declaração de Helsínquia" da Associação Médica Mundial
(Helsínquia 1964; Tóquio 1975; Veneza 1983; Hong Kong 1989; Somerset West 1996; Edimburgo 2000; Washington 2002; Tóquio 2004;Seoul 2008)

Designação do Estudo: Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares

Eu, abaixo-assinado, (nome completo do participante no estudo) _____ _____, declaro que fui informado:

- Acerca dos objetivos e finalidade do estudo acima mencionado;
- Acerca dos questionários que vão ser utilizados;
- Que os dados relativos à identificação dos participantes são confidenciais;
- Que será mantido o anonimato;
- Que posso recusar-me a participar no estudo;
- Que posso interromper a qualquer momento a participação no estudo, sem qualquer prejuízo.

Declaro que compreendi a informação que me foi dada, tive oportunidade de fazer perguntas e as minhas dúvidas foram esclarecidas.

Aceito participar de livre vontade no estudo acima mencionado.

Autorizo a utilização dos dados obtidos para efeitos científicos e académicos.

Data: ____ / _____ / 201__

Assinatura do participante no estudo: _____

(A preencher pelo Terapeuta da Fala)

Declaro que todos os questionários foram lidos em voz alta e que todas as respostas foram registadas de acordo com a opinião do participante.

Assinatura do Terapeuta da Fala: _____

O Investigador responsável:

Nome: Ana Brígida Francisco Patrício

Assinatura:

Appendix W: Informed consent for the caregivers

DECLARAÇÃO DE CONSENTIMENTO

Considerando a "Declaração de Helsínquia" da Associação Médica Mundial
(Helsínquia 1964; Tóquio 1975; Veneza 1983; Hong Kong 1989; Somerset West 1996; Edimburgo 2000; Washington 2002; Tóquio 2004;Seoul 2008)

Designação do Estudo: Impacto das alterações da comunicação na qualidade de vida das pessoas com afasia e na dos seus familiares

Eu, abaixo-assinado, (nome completo do participante no estudo) _____ _____, declaro que fui informado:

- Acerca dos objetivos e finalidade do estudo acima mencionado;
- Acerca dos questionários que vão ser utilizados;
- Que os dados relativos à identificação dos participantes são confidenciais;
- Que será mantido o anonimato;
- Que posso recusar-me a participar no estudo;
- Que posso interromper a qualquer momento a participação no estudo, sem qualquer prejuízo.

Declaro que compreendi a informação que me foi dada, tive oportunidade de fazer perguntas e as minhas dúvidas foram esclarecidas.

Aceito participar de livre vontade no estudo acima mencionado.

Autorizo a utilização dos dados obtidos para efeitos científicos e académicos.

Data: ____ / _____ / 201__

Assinatura do participante no estudo: _____

(A preencher pelo Terapeuta da Fala caso, por dificuldades de leitura e/ou escrita, os questionários tenham sido lidos e respondidos com a sua ajuda)

Declaro que todos os questionários foram lidos em voz alta e que todas as respostas foram registadas de acordo com a opinião do participante.

Assinatura do Terapeuta da Fala: _____

O Investigador responsável:
Nome: Ana Brígida Francisco Patrício
Assinatura:

Appendix X: Table results for study 1 (Portuguese general population sample)

X.1. Study 1 (Portuguese general population sample)

X.1.1. Quality of life of Portuguese general population

Table X.1: Overall QOL and QOL domains correlations (WHOQOL-Bref)

Correlations (Spearman's rho)					
		Physical	**Psychological**	**SR**	**Environment**
Overall QOL	Correlation Coefficient	0.558**	0.499**	0.335**	0.452**
	Sig. (2-tailed)	0.000	0.000	0.000	0.000
	N	255	255	255	255

**. Correlation is significant at the 0.01 level (2-tailed).

Table X.2: Overall QOL and WHOQOL-100 SR domain correlation

Correlations (Spearman's rho)		
		SR WHOQOL-100
Overall QOL	Correlation Coefficient	0.366**
	Sig. (2-tailed)	0.000
	N	255

**. Correlation is significant at the 0.01 level (2-tailed).

Table X.3: Correlations between overall QOL and Age, Educational level, Socieconomic status, Number of cohabitants and Emotional status

Correlations (Spearman's rho)					
		Overall QOL	**Age**	**Educational level**	**Socioeconomic status**
Overall QOL	Correlation Coefficient	1	-0.265**	0.333**	-0.141*
	Sig. (2-tailed)	.	0.000	0.000	0.024
	N	255	255	255	255
Number of cohabitants	Correlation Coefficient	0.015			
	Sig. (2-tailed)	0.817	-	-	-
	N	255			
Emotional status	Correlation Coefficient	-0.337**			
	Sig. (2-tailed)	0.000	-	-	-
	N	255			

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table X.4: Chi-Square for QOL and Gender

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.495a	6	0.745
Likelihood Ratio	3.510	6	0.743
N of Valid Cases	255		

a. 4 cells (28.6%) have expected count less than 5. The minimum expected count is 1.68.

X.1.2. Social relationships of Portuguese general population

Table X.5: Linear regression for SR domain (WHOQOL-Bref)

Linear regression (stepwise)			ANOVA(c)		
Model	R	R Square	df	F	Sig.
1	0.491ª	0.242	1;253	80.559	0.000a
2	0.509b	0.259	2; 252	44.118	0.000b

a. Predictors: (Constant), Emotional Status
b. Predictors: (Constant), Emotional Status, Age
c. Dependent Variable: SR domain

Table X.6: SR domains as predictors of overall QOL

Linear regression		
Model	R	R Square
1	0.365a	0.133

a. Predictors: (Constant), WHOQOL-100 SR

Table X.7: SR domain of WHOQOL-Bref and its items correlation

Correlations (Spearman's rho)				
		Item 20	**Item 21**	**Item 22**
SR WHOQOL-Bref	Correlation Coefficient	0.764**	0.819**	0.768**
	Sig. (2-tailed)	0.000	0.000	0.000
	N	255	255	255

**. Correlation is significant at the 0.01 level (2-tailed).

Table X.8: SR WHOQOL-Bref items predictors for SR results

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.818ª	0.669	1; 253	510.805	0.000a
2	0.948b	0.899	2; 252	1130.000	0.000b
3	1.000c	1	3; 251	.	0.000c

a. Predictors: (Constant), Item 21
b. Predictors: (Constant), Item 21, Item 22
c. Predictors: (Constant), Item 21, Item 22, Item 20
d. Dependent Variable: SR WHOQOL-Bref

Table X.9: WHOQOL-100 SR items as predictors of overall WHOQOL-100 SR

Linear regression		
Model	R	R Square
1	0.821a	0.674
2	0.895b	0.800
3	0.943c	0.889
4	0.960d	0.922
5	0.973e	0.946

a. Predictors: (Constant), Item 10;
b. Predictors: (Constant), Item 10, Item 7;
c. Predictors: (Constant), Item 10, Item 7, Item 5;
d. Predictors: (Constant), Item 10, Item 7, Item 5, Item 11;
e. Predictors: (Constant), Item 10, Item 7, Item 5, Item 11, Item 1

Appendix Y: Table results for study 2 (People with aphasia sample)

Y.1. Study 2 (People with aphasia sample)

Y.1.1. Quality of life of people with aphasia

Table Y.1: PWA's overall QOL correlation with WHOQOL-100 SR domain

Correlations (Spearman's rho)		
		SR WHOQOL-100
Overall QOL	Correlation Coefficient	0.720**
	Sig. (2-tailed)	0.000
	N	25

**. Correlation is significant at the 0.01 level (2-tailed).

Table Y.2: Kruskal Wallis for Overall QOL and gender, marital status, type of cohabitants, occupation and health (PCA)

		Overall QOL
Gender	Chi-Square	0.554
	Df	1
	Asymp. Sig.	0.457
Marital Status	Chi-Square	0.281
	Df	3
	Asymp. Sig.	0.964
Type of cohabitants	Chi-Square	1.089
	Df	5
	Asymp. Sig.	0.955
Occupation	Chi-Square	4.487
	Df	4
	Asymp. Sig.	0.344
Health	Chi-Square	1.782
	Df	1
	Asymp. Sig.	0.182

Table Y.3: QOL correlations with time after discharge, SLT time and the time PWA's left SLT

Correlations (Spearman's rho)				
		Time discharged	**SLT time**	**Time left SLT**
Overall QOL	Correlation Coefficient	0.139	0.198	-0.577
	Sig. (2-tailed)	0.508	0.343	0.231
	N	25	25	6

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table Y.4: Kruskal-Wallis for Overall QOL and motor impairment, aphasia etiology and having SLT currently or in the past

		Overall QOL
Motor impairment	Chi-Square	4.878
	df	2
	Asymp. Sig.	0.087
Aphasia etiology	Chi-Square	0.542
	df	1
	Asymp. Sig.	0.462
Having SLT	Chi-Square	2.598
	df	1
	Asymp. Sig.	0.107

Table Y.5: QOL domains as PWA's overall QOL predictors

Linear regression (Stepwise)			ANOVA(c)		
Model	R	R Square	df	F	Sig.
1	0.872ª	0.76	1; 23	72.891	0.000a
2	0.902b	0.813	2;22	47.846	0.000b

a. Predictors: (Constant), Physical Domain
b. Predictors: (Constant), Physical Domain, Environmental domain
c. Dependent Variable: Overall QOL

Table Y.6: SR domains (WHOQOL-Bref and WHOQOL-100) as PWA's overall QOL predictors

Linear regression (Stepwise)			ANOVA(b)		
Model	R	R Square	df	F	Sig.
1	0.780ª	0.609	1; 23	35.814	0.000a

a. Predictors: (Constant), WHOQOL-Bref SR
b. Dependent Variable: Overall QOL

Table Y.7: PWA's overall QOL predictors

Linear regression (Stepwise)			ANOVA(c)		
Model	R	R Square	df	F	Sig.
1	0.744	0.553	1; 23	28.448	0.000a
2	0.792	0.627	2; 22	18.461	0.000b

a. Predictors: (Constant), Participation (CDP)
b. Predictors: (Constant), Participation (CDP), Emotional Status
c. Dependent Variable: Overall QOL

Y.1.2. Social relationships of people with aphasia

Table Y.8: Correlation between PWA's SR domains and age, educational level, socioeconomic status and number of cohabitants

Correlations (Spearman's rho)					
		SR (WHOQOL-Bref)	**SR (WHOQOL-100)**	**Age**	**Education Level**
SR (WHOQOL-Bref)	Correlation Coefficient	1	0.901**	0.310	0.383
	Sig. (2-tailed)	.	0	0.131	0.059
	N	25	25	25	25
SR (WHOQOL-100)	Correlation Coefficient	0.901**	1	0.103	0.392
	Sig. (2-tailed)	0	.	0.625	0.053
	N	25	25	25	25
Socioeconomic Status	Correlation Coefficient	-0.286	-0.203		
	Sig. (2-tailed)	0.166	0.329	-	-
	N	25	25		
Number of cohabitants	Correlation Coefficient	-0.238	-0.255		
	Sig. (2-tailed)	0.253	0.219	-	-
	N	25	25		

**. Correlation is significant at the 0.01 level (2-tailed).

Table Y.9: Correlation between PWA's SR domains and time after discharge, SLT time and time PWA's left SLT

Correlations (Spearman's rho)				
		Time Discharged	**SLT time**	**Time left SLT**
SR WHOQOL-Bref	Correlation Coefficient	-0.009	0.157	-0.588
	Sig. (2-tailed)	0.966	0.452	0.219
	N	25	25	6
SR WHOQOL-100	Correlation Coefficient	0.045	0.229	-0.314
	Sig. (2-tailed)	0.831	0.270	0.544
	N	25	25	6

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table Y.10: Kruskal-Wallis for Overall SR and Age, marital status, type of cohabitants, occupation, health, motor impairment, aphasia etiology and SLT currently or in the past (PWA)

		SR WHOQOL-Bref	SR WHOQOL 100
Gender	Chi-Square	0.037	0.859
	Df	1	1
	Asymp. Sig.	0.847	0.354
Marital status	Chi-Square	1.804	2.788
	Df	2	2
	Asymp. Sig.	0.406	0.248
Type of cohabitants	Chi-Square	2.930	4.988
	Df	5	5
	Asymp. Sig.	0.711	0.417
Occupation	Chi-Square	5.143	5.583
	Df	4	4
	Asymp. Sig.	0.273	0.233
Health	Chi-Square	1.262	0.391
	Df	1	1
	Asymp. Sig.	0.261	0.532
Motor impairment	Chi-Square	1.823	3.23
	Df	2	2
	Asymp. Sig.	0.402	0.199
Aphasia etiology	Chi-Square	0.001	0.059
	Df	1	1
	Asymp. Sig.	0.976	0.808
SLT currently or past	Chi-Square	0.004	0.037
	Df	1	1
	Asymp. Sig.	0.949	0.848

Table Y.11: PWA's SR predictors

Linear regression (stepwise)			ANOVA(c)		
Model	R	R Square	df	F	Sig.
1	0.687a	0.472	1; 23	20.523	0.000a
2	0.761b	0.58	2; 22	15.161	0.000a

a. Predictors: (Constant), Participation (CDP)

b. Predictors: (Constant), Participation (CDP), Age

c. Dependent Variable: SR domain

Table Y.12: SR WHOQOL-Bref items correlations for PWA's group

Spearman's rho				
		Item 20	**Item 21**	**Item 22**
SR WHOQOL-Bref	Correlation Coefficient	0.808**	0.856**	0.919**
	Sig. (2-tailed)	0.000	0.000	0.000
	N	25	25	25

**. Correlation is significant at the 0.01 level (2-tailed).

Table Y.13: SR WHOQOL-100 items correlations for PWA's group

Spearman's rho							
		SR WHOQOL-100	**Item 1**	**Item 2**	**Item 3**	**Item 4**	**Item 5**
SR WHOQOL-100	Correlation Coefficient	1	-0.624**	0.526**	-0.728**	0.840**	0.860**
	Sig. (2-tailed)	.	0.001	0.007	0.000	0.000	0.000
	N	25	25	25	25	25	25
Item 6	Correlation Coefficient	0.887**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 7	Correlation Coefficient	0.828**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 8	Correlation Coefficient	0.622**					
	Sig. (2-tailed)	0.001	-	-	-	-	-
	N	25					
Item 9	Correlation Coefficient	0.867**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 10	Correlation Coefficient	0.634**					
	Sig. (2-tailed)	0.001	-	-	-	-	-
	N	25					
Item 11	Correlation Coefficient	0.768**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					
Item 12	Correlation Coefficient	0.654**					
	Sig. (2-tailed)	0.000	-	-	-	-	-
	N	25					

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).
Items 6, 7 and 9 take part in WHOQOL-Bref

Table Y.14: WHOQOL-Bref SR items as predictor of PWA's SR results

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.935a	0.874	1;23	159.956	0.000a
2	0.968b	0.937	2; 22	164.49	0.000b
3	0.994c	0.988	3; 21	570.737	0.000c

a. Predictors: (Constant), Item 22
b. Predictors: (Constant), Item 22, Item 21
c. Predictors: (Constant), Item 22, Item 21, Item 20
d. Dependent Variable: SR WHOQOL-Bref

Table Y.15: WHOQOL-100 SR items as predictors of PWA's SR results

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.891a	0.793	1; 23	88.127	0.000a
2	0.959b	0.919	2; 22	124.903	0.000b
3	0.968c	0.937	3; 21	103.393	0.000c

a. Predictors: (Constant), Item 5
b. Predictors: (Constant), Item 5, Item 3
c. Predictors: (Constant), Item 5, Item 3, Item 6
d. Dependent Variable: SR WHOQOL-100

Y.1.3. People's with aphasia and Portuguese general population's overall quality of life and social relationships comparisons

Table Y.16: Independent Samples t test for equality of groups' ages (control and PWA)

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Age	Equal variances assumed	0.118	0.732	0.202	73	0.840	0.700	3.463	-6.203	7.603
	Equal variances not assumed			0.197	44.828	0.845	0.700	3.558	-6.467	7.867

Table Y.17: Mann-Whitney for educational level comparison between groups (control and PWA)

	Education Level
Mann-Whitney U	604.500
Wilcoxon W	929.500
Z	-0.235
Asymp. Sig. (2-tailed)	0.814

a. Grouping Variable: Group

Appendix Z: Table results for study 3 (Caregivers sample)

Z.1. Study 3 (Caregivers sample)

Z.1.1. Quality of life of people's with aphasia caregivers

Table Z.1: Caregivers' overall QOL correlations with QOL domains (WHOQOL-Bref)

Correlations (Spearman's rho)					
		Physical	**Psychological**	**SR**	**Environment**
Overall QOL	Correlation Coefficient	0.540**	0.623**	0.472*	0.710**
	Sig. (2-tailed)	0.005	0.001	0.017	0.000
	N	25	25	25	25

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table Z.2: Caregivers' overall QOL correlation with WHOQOL-100 SR domain

Spearman's rho		
		SR WHOQOL-100
Overall QOL	Correlation Coefficient	0.459*
	Sig. (2-tailed)	0.021
	N	25

*. Correlation is significant at the 0.05 level (2-tailed).

Table Z.3: The use of coping strategies - CAMI's items frequencies

CAMI items		**Do not use**	**Not really helpful**	**Quite helpful**	**Really helpful**	**Total**
1	Frequency	14	0	9	2	25
	Percent	56	0	36	8	100
2	Frequency	13	7	4	1	25
	Percent	52	28	16	4	100
3	Frequency	8	0	10	7	25
	Percent	32	0	40	28	100
4	Frequency	8	0	10	7	25
	Percent	32	0	40	28	100
5	Frequency	9	3	7	6	25
	Percent	36	12	28	24	100
6	Frequency	15	1	7	2	25
	Percent	60	4	28	8	100
7	Frequency	4	0	15	6	25
	Percent	16	0	60	24	100
8	Frequency	15	3	6	1	25
	Percent	60	12	24	4	100
9	Frequency	5	0	9	11	25
	Percent	20	0	36	44	100

Table Z.3: The use of coping strategies - CAMI's items frequencies (continued)

CAMI items		Do not use	Not really helpful	Quite helpful	Really helpful	Total
10	Frequency	3	0	12	10	25
	Percent	12	0	48	40	100
11	Frequency	5	1	5	14	25
	Percent	20	4	20	56	100
12	Frequency	2	0	6	17	25
	Percent	8	0	24	68	100
13	Frequency	4	1	14	6	25
	Percent	16	4	56	24	100
14	Frequency	9	0	8	8	25
	Percent	36	0	32	32	100
15	Frequency	9	0	8	8	25
	Percent	36	0	32	32	100
16	Frequency	3	1	12	9	25
	Percent	12	4	48	36	100
17	Frequency	3	1	11	10	25
	Percent	12	4	44	40	100
18	Frequency	5	1	9	10	25
	Percent	20	4	36	40	100
19	Frequency	8	4	10	3	25
	Percent	32	16	40	12	100
20	Frequency	2	1	18	4	25
	Percent	8	4	72	16	100
21	Frequency	6	0	16	3	25
	Percent	24	0	64	12	100
22	Frequency	15	6	2	2	25
	Percent	60	24	8	8	100
23	Frequency	3	2	15	5	25
	Percent	12	8	60	20	100
24	Frequency	7	1	8	9	25
	Percent	28	4	32	36	100
25	Frequency	1	0	10	14	25
	Percent	4	0	40	56	100
26	Frequency	5	4	14	2	25
	Percent	20	16	56	8	100
27	Frequency	3	3	15	4	25
	Percent	12	12	60	16	100
28	Frequency	14	2	6	3	25
	Percent	56	8	24	12	100
29	Frequency	1	0	16	8	25
	Percent	4	0	64	32	100

Table Z.3: The use of coping strategies - CAMI's items frequencies (continued)

CAMI items		Do not use	Not really helpful	Quite helpful	Really helpful	Total
30	Frequency	4	1	14	6	25
	Percent	16	4	56	24	100
31	Frequency	7	0	11	7	25
	Percent	28	0	44	28	100
32	Frequency	5	0	11	9	25
	Percent	20	0	44	36	100
33	Frequency	11	0	8	6	25
	Percent	44	0	32	24	100
34	Frequency	6	0	11	8	25
	Percent	24	0	44	32	100
35	Frequency	15	2	5	3	25
	Percent	60	8	20	12	100
36	Frequency	19	0	5	1	25
	Percent	76	0	20	4	100
37	Frequency	21	0	4	0	25
	Percent	84	0	16	0	100
38	Frequency	6	0	12	7	25
	Percent	24	0	48	28	100

Table Z.4: Kruskal Wallis for overall QOL and gender, marital status, type of cohabitants, occupation and health (Caregivers)

		Overall QOL
Gender	Chi-Square	2.955
	df	1
	Asymp. Sig.	0.086
Marital status	Chi-Square	4.314
	df	4
	Asymp. Sig.	0.365
Type of cohabitants	Chi-Square	2.468
	df	5
	Asymp. Sig.	0.781
Occupation	Chi-Square	1.116
	Df	2
	Asymp. Sig.	0.572
Health	Chi-Square	0.401
	Df	1
	Asymp. Sig.	0.526

Table Z.5: Correlation between QOL and Time post-stroke, Aphasia severity, activities (BI, FAI and CDP), participation and cognition

Correlations (Spearman's rho)					
		Overall QOL	**Time post-stroke (months)**	**Aphasia coefficient**	**Activities (BI)**
Overall QOL	Correlation Coefficient	1	0.036	0.305	0.350
	Sig. (2-tailed)		0.864	0.139	0.086
	N	25	25	25	25
Activities (FAI)	Correlation Coefficient	0.341			
	Sig. (2-tailed)	0.095	-	-	-
	N	25			
Activities (CDP)	Correlation Coefficient	-0.462*			
	Sig. (2-tailed)	0.020	-	-	-
	N	25			
Participation (CDP)	Correlation Coefficient	-0.558**			
	Sig. (2-tailed)	0.004	-	-	-
	N	25			
Cognition	Correlation Coefficient	0.293			
	Sig. (2-tailed)	0.156	-	-	-
	N	25			

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table Z.6: Correlation between caregivers' QOL and time after discharge, SLT time and time PWA's left SLT

Correlations (Spearman's rho)				
		Time Discharged	**SLT time**	**Time left SLT**
Overall QOL	Correlation Coefficient	0.062	0.237	-0.580
	Sig. (2-tailed)	0.768	0.255	0.306
	N	25	25	5

**. Correlation is significant at the 0.01 level (2-tailed).

Table Z.7: Kruskal Wallis for caregivers' QOL and motor impairment, aphasia etiology and PWA's having SLT currently or in the past

		Overall QOL
Motor impairment	Chi-Square	2.996
	Df	2
	Asymp. Sig.	0.224
Aphasia etiology	Chi-Square	1.794
	Df	1
	Asymp. Sig.	0.180
SLT currently or past	Chi-Square	0.544
	Df	1
	Asymp. Sig.	0.461

Table Z.8: QOL domains as predictors of caregivers' overall QOL

Linear regression (stepwise)			ANOVA(b)		
Model	R	R Square	df	F	Sig.
1	0.734a	0.539	1; 23	26.902	0.000a

a. Predictors: (Constant), Psychological Domain
b. Dependent Variable: Overall QOL

Table Z.9: SR domains (WHOQOL-Bref and WHOQOL-100) as caregivers' overall QOL predictors

Linear regression (stepwise)			ANOVA(b)		
Model	R	R Square	df	F	Sig.
1	0.425a	0.181	1; 23	5.077	0.034a

a. Predictors: (Constant), SR WHOQOL-Bref
b. Dependent Variable: Overall QOL

Z.1.2. Social relationships of people's with aphasia caregivers

Table Z.10: Correlations between caregivers' SR domains and time after discharge, SLT time and the time PWA left SLT

Correlations (Spearman's rho)				
		Time Discharged	**SLT time**	**Time left SLT**
SR WHOQOL-Bref	Correlation Coefficient	0.015	0.274	-0.580
	Sig. (2-tailed)	0.942	0.185	0.306
	N	25	25	5
SR WHQOOL-100	Correlation Coefficient	-0.011	0.292	-0.600
	Sig. (2-tailed)	0.958	0.156	0.285
	N	25	25	5

**. Correlation is significant at the 0.01 level (2-tailed).

Table Z.11: Kruskal-Wallis for SR and gender, marital status, type of cohabitants, occupation, health, motor impairment, aphasia etiology, and STL currently or in the past (Caregivers)

		SR WHOQOL-Bref	SR WHOQOL-100
Gender	Chi-Square	0.032	0.123
	df	1	1
	Asymp. Sig.	0.859	0.726
Marital status	Chi-Square	0.739	0.870
	df	3	3
	Asymp. Sig.	0.864	0.833
Type of cohabitants	Chi-Square	2.293	2.219
	df	5	5
	Asymp. Sig.	0.807	0.818
Occupation	Chi-Square	0.061	1.626
	Df	2	2
	Asymp. Sig.	0.97	0.444
Health	Chi-Square	0.094	0.204
	Df	1	1
	Asymp. Sig.	0.76	0.652
Motor impairment	Chi-Square	0.426	0.85
	Df	2	2
	Asymp. Sig.	0.808	0.654
Aphasia etiology	Chi-Square	0.343	0.004
	Df	1	1
	Asymp. Sig.	0.558	0.952
SLT currently or past	Chi-Square	1.940	0.229
	Df	1	1
	Asymp. Sig.	0.164	0.633

Table Z.12: Caregivers' SR predictors

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.573a	0.328	1; 23	11.221	0.003a
2	0.747b	0.558	2; 22	13.903	0.000b
3	0.800c	0.639	3; 21	12.402	0.000c

a. Predictors: (Constant), Number of cohabitants
b. Predictors: (Constant), Number of cohabitants, Participation (CDP)
c. Predictors: (Constant), Number of cohabitants, Participation (CDP), Emotional Status
d. Dependent Variable: SR domain

Table Z.13: SR WHOQOL-Bref items correlations for caregivers' group

Spearman's rho				
		Item 20	**Item 21**	**Item 22**
SR WHOQOL-Bref	Correlation Coefficient	0.867**	0.604**	0.895**
	Sig. (2-tailed)	0.000	0.001	0.000
	N	25	25	25

**. Correlation is significant at the 0.01 level (2-tailed).

Table Z.14: Table: WHOQOL-Bref SR items as predictor of caregivers' SR results

Linear regression (stepwise)			ANOVA(d)		
Model	R	R Square	df	F	Sig.
1	0.903a	0.816	1; 23	101.722	0.000a
2	0.978b	0.956	2; 22	240.665	0.000b
3	1.000c	1	3; 21	.	0.000c

a. Predictors: (Constant), Item 22
b. Predictors: (Constant), Item 22, Item 21
c. Predictors: (Constant), Item 22, Item 21, Item 20
d. Dependent Variable: SR WHOQOL-Bref

Table Z.15: WHOQOL-100f SR items as predictor of caregivers' SR results

Linear regression (stepwise)			ANOVA(f)		
Model	R	R Square	df	F	Sig.
1	0.821a	0.673	1; 23	47.441	0.000a
2	0.920b	0.847	2; 22	61.03	0.000b
3	0.952c	0.906	3; 21	67.169	0.000c
4	0.962d	0.926	4; 20	62.434	0.000d
5	0.972e	0.945	5; 19	65.769	0.000e

a. Predictors: (Constant), Item 5
b. Predictors: (Constant), Item 5, Item 12
c. Predictors: (Constant), Item 5, Item 12, Item 8
d. Predictors: (Constant), Item 5, Item 12, Item 8, Item 9
e. Predictors: (Constant), Item 5, Item 12, Item 8, Item 9, Item 4
f. Dependent Variable: SR WHOQOL-100

Z.1.3. Caregivers', people's with aphasia and Portuguese general population overall quality of life and social relationships comparisons

Table Z.16: Independent Samples t test for equality of groups' ages (control and caregivers)

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	Df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Age	Equal variances assumed	0.533	0.468	-0.261	73	0.795	-0.920	3.530	-7.955	6.115
	Equal variances not assumed			-0.251	43.541	0.803	-0.920	3.668	-8.314	6.474

Table Z.17: Mann-Whitney for educational level comparison between groups (control and caregivers)

	Education Level
Mann-Whitney U	608.500
Wilcoxon W	1883.500
Z	-0.192
Asymp. Sig. (2-tailed)	0.847

a. Grouping Variable: Group

Table Z.18: Mann-Whitney for overall QOL and SR comparison between groups (control and caregivers)

Overall QOL	Mann-Whitney U	466.500
	Wilcoxon W	791.500
	Z	-1.898
	Asymp. Sig. (One-tailed)	0.029
SR WHOQOL-Bref	Mann-Whitney U	423.500
	Wilcoxon W	748.500
	Z	-2.288
	Asymp. Sig. (One-tailed)	0.011

a. Grouping Variable: Group

Table Z.19: Independent Samples t test for equality of groups' ages (PWA and caregivers)

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Age	Equal variances assumed	0,172	0,680	0,614	48	0,542	2,640	4,301	-6,007	11,287
	Equal variances not assumed			0,614	47,923	0,542	2,640	4,301	-6,008	11,288

Table Z.20: Mann-Whitney for educational level comparison between groups (PWA and caregivers)

	Education Level
Mann-Whitney U	233,500
Wilcoxon W	558,500
Z	-1,570
Asymp. Sig. (2-tailed)	0,116

a. Grouping Variable: Group

Table Z.21: Mann-Whitney for overall QOL and SR comparison between groups (PWA and caregivers)

Overall QOL	Mann-Whitney U	171.500
	Wilcoxon W	496.500
	Z	-2.798
	Asymp. Sig. (One-tailed)	0.0025
SR WHOQOL-Bref	Mann-Whitney U	262.000
	Wilcoxon W	587.000
	Z	-0.995
	Asymp. Sig. (One-tailed)	0.16

a. Grouping Variable: Group